

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN3613001

Exhibits: **N/A**

Dated: 10th June 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 July 2019.

I **GRO-B** will say as follows: -

Section 1. Introduction

1. My name is **GRO-B** My date of birth is the **GRO-B** 1970 and my address is known to the Inquiry. I am on disability benefit and unable to work due to ill-health. I intend to speak about my husband **GRO-B: H** and his infection of hepatitis C; in particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our family.

2. I met **H** in 2008. I had been married previously and had four daughters to my ex-husband. When I met **H** **GRO-B**
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3. [H] and I were married in [GRO-B]. My girls took on his name. We were and remain a very close and loving family. [H] was a brilliant father and would do anything for me and the girls.

Section 2. How Affected

4. [H] told me when we met that he had a condition that 'runs in the royal family'. I asked him if he had haemophilia and he confirmed he did. He also told me that he had hepatitis C that he had got from receiving contaminated blood products.
5. [H] didn't really talk much about his hepatitis C infection. I knew what hepatitis C was because in my younger days I worked in nursing at [GRO-B]. [GRO-B] I was working on an isolation ward. There were patients on the ward who had HIV and hepatitis C.
6. [H] has told me that he has had a lot of Factor VIII blood products throughout his life when he had bleeds. It was on one of these occasions that he had been given blood products that were contaminated and as a result he contracted hepatitis C.
7. [H] has told me that he and his mother were never told that there were any risks of being exposed to infection from blood products.
8. [H] told me that when we met in 2008 that he had been told in 1993 that he had hepatitis C. I knew there was a small risk of others being infected but as a family it was not something that concerned us.
9. [H] and I were married in [GRO-B]. I knew [H] wanted a child of his own so we started trying to have a baby as soon as we were married. [H] and I didn't really talk about any risk of me contracting hepatitis C through sexual intercourse. I knew the risk was very low and I knew how much it meant to [H] to have a child. Sadly we tried for 10 years without success.

Section 3. Other Infections

10. As well as hepatitis C [H] has been told that he may have contracted vCJD. He received blood products from a blood donor who had died from vCJD. There is no test for this disease. It is only discovered if you start to get symptoms or at a post-mortem after death. [H] and I have to live with this knowledge every day and it is very worrying.

Section 4. Consent

11. I do not know if [H] was treated or tested for the purposes of research but [H] strongly believes he was.

Section 5. Impact

12. The impact of [H] contracting hepatitis C has meant that he developed cirrhosis of the liver and has received a death sentence. Physically [H] is always tired and very weak. We are in the process of moving house at the moment and [H] is unable to assist in packing and moving furniture. He is just physically unable to help.

13. The hepatitis C has caused [H] to have cirrhosis of the liver. He was told five years ago by medical professionals that he had five years to live. Five years is up now so we just live for each and every day. I see [H] deteriorate every day and it is heart breaking.

14. On the 1st May 2019 [H] was in a lot of pain around his abdomen. He thought his liver was failing and he was going to die. He was saying things like "tell the girls I love them". He was very jaundiced. I phoned the doctor to come out. [H] didn't want me to because he thought he was dying and he wanted to die at home and not in a hospital; such was his mistrust of the health service. Eventually [GRO-B] came out and examined [H] [GRO-B] said it was [H] gallbladder that was the problem.

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15. When **GRO-B** came out he handed me **H** medical notes. I noticed that there was an entry written on the 10th February 1993 that stated that **H** was hepatitis C positive. It said he had hepatitis C related cirrhosis, non-alcohol-related through contaminated blood products. I couldn't believe it because **H** had only been told he had cirrhosis in 2012. I took a screenshot of this medical entry on my phone. **H** produces this screenshot in evidence to the Inquiry. The reason I did this was because I was disgusted that it was known that **H** had hepatitis C in 1993 yet he hadn't been told until 2012. Perhaps if he had been told earlier **H** could have received treatment earlier and we would not be facing this death sentence.

16. In 2015 **H** had a three-month course of treatment for hepatitis. This consisted of taking tablets called ribavirin and sofosbuvir. This treatment was offered to **H**. We were told it was a new treatment that was available. At first **H** did not want to take the treatment. He had received treatment previously that had been unsuccessful and had made him very poorly. Eventually **H** decided to take the treatment because he was desperate to get rid of the infection because of the stigma attached to it.

17. The side-effects of the treatment were brutal on **H** physical and mental health. Physically **H** had severe flu-like symptoms. He lost a lot of weight. He went from a size 42 inch waist to a 30 inch waist. He had the shivers and sweats constantly. He complained of feeling nauseous all the time. He was constantly tired. Mentally, he became very depressed, he was withdrawn and very agitated. He practically locked himself away for the three months. He didn't want to go out and he didn't want to see or speak to anyone. **H** developed brain fog. Prior to the treatment **H** would deal with the household finances. Mentally he couldn't concentrate and things became very muddled for him. I had to take over this responsibility. He forgot birthdays and even his telephone number that he had used for years. **H** became very irritable and almost a different person. The treatment

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was successful. I thought [H] health would improve with the success of the treatment. If anything his health has got worse. He can't walk barefoot as he complains of pins and needles in his feet he is constantly fatigued and struggles to stand.

18. I do not know if [H] infected status impacted on his medical or dental care for any other condition.

19. In 2012 [H] became very ill. He was struggling to walk and his belly became very swollen. He was constantly tired and became very confused. He would say things like [GRO-B] "have I seen the kids today" [H] was going to see Professor [GRO-D] the liver specialist at Edinburgh Royal infirmary. I would always go with him. [H] would tell the Professor his symptoms. Professor [GRO-D] appeared to dismiss [H] He would say to him "you're a medical mystery" [H] would also see the liver specialist nurse [GRO-D] [GRO-D]. He would tell her his symptoms and say how unwell he felt. She also seemed to dismiss [H] she couldn't understand what was wrong with him. [H] would get very angry and I would get very frustrated. They made [H] feel very stupid almost as if he was making up his symptoms.

20. I remember I phoned the British Liver Trust and spoke to a lady called Sarah Tattersall. I explained [H] symptoms to her. She confirmed that all [H] symptoms were consistent with liver failure.

21. At the end of September 2012 [H] went to his own doctor, [GRO-B] [GRO-B]. He had his blood taken for testing. A few days after this [H] received a phone call from his doctor who told him he had liver failure and it was very serious. He told him to go straight to Edinburgh Infirmary. [H] and I went straight to see Dr Horner at Edinburgh Haemophilia Centre. [H] had more bloods taken from him [H] was sent for a fibro scan on his liver. I remember the nurse kept trying to do the scan but she couldn't get a reading. Eventually she managed to get a reading and said "oh my god I'm shocked you're reading is 38.3 and even people with cirrhosis are sometimes between 16 and 18" [H] was taken back to the

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ward and I sat by his bedside. I remember it was a Friday evening. Professor [GRO-D] came over to the bed and told [H] he was keeping him in over the weekend. That is all he said and he went to walk away. I shouted him back and said "has [H] got cirrhosis of the liver" and the Professor replied "yes". I couldn't believe he was going to leave [H] over the weekend without telling him. On the Monday [H] was taken to see Professor [GRO-D] I was with him. There was another doctor and a nurse there. I believe the other doctor was called Dr Woolsey-Dennis. I don't know the name of the nurse. [H] asked Professor [GRO-D] how bad his condition was and Professor [GRO-D] just played it down saying [H] was middle of the range. Both [H] and I knew this wasn't true because of what the nurse said who took his fibro scan. [H] told him what his reading was but Professor [GRO-D] played it down and said his reading could go higher.

22 [H] and I are aware of the stigma associated with hepatitis C. It is associated with homosexuality and intravenous drug users. [H] and I didn't broadcast his infection because of the stigma. Despite being very ill when he was taking his treatment it was because of the stigma and the desperate need for him to be rid of the infection that he persevered.

23. Since 2012 [H] illness has took its toll on me. I am not in good health myself but I have had to be [H] carer. I am so scared of the future. I do not want to lose [H] I love him so much.

24 [H] and I tried for 10 years to have a baby together. We later found out that hepatitis C can damage sperm and it was almost impossible for me to conceive. This has affected [H] and I very much as we dearly wanted our own child together.

25 [H] has been too ill to be able to work and we have both struggled financially. Around the time of the Penrose Inquiry people who had been infected were told they would receive substantial compensation. [H] and I decided we would rent until we received the money and then we would

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buy a house. This has never happened and we are having to downsize as the rent on the bungalow we are currently living in is too expensive.

Section 6. Treatment/Care/Support

26. [H] and I have never been offered counselling or psychological support. [H] is very mistrustful of the NHS and he believes he has been deceived for many years. Having seen the entry on his medical notes saying he was diagnosed with cirrhosis of the liver in 1993 I have to agree with him. They knew [H] had cirrhosis for many years but no one told him.

Section 7. Financial Assistance

27. [H] had received a lump sum of money for being infected with contaminated blood from the Skipton fund. This was before I had met him he told me he had received £20,000. I cannot comment on the process of applying for this money as it was before I met him.
28. When [H] was told in 2012 that he had cirrhosis of the liver the hospital applied to the Skipton fund on his behalf. He received £50,000 [H] also receives £2200 every month from the Scottish government.
29. [H] and I both worry about my future after he has gone. I fear I will end up in a council flat and not be able to have my beloved dogs live with me. [H] wants to know that I will be financially secure after he is gone. It is doubtful that [H] will see the outcome of this Inquiry. This is a great source of sadness for us both.

Section 8. Other Issues

30. I do wish to remain anonymous in this Inquiry.

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Statement of Truth

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

Signed

GRO-B

Dated Jun 10, 2020