

Witness Name: GRO-B

Statement No: WITN5267001

Exhibits: 0

Dated: December 2020

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.
GRO-B
2. My husband GRO-B (born on GRO-B), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII). He died GRO-B 2020, aged 54.
3. This witness statement has been prepared without the benefit of access to GRO-B's full medical records.

Section 2. How Affected

4. GRO-B had severe Haemophilia A, diagnosed at birth. He was under the care of Dr Wensley and then Professor Hay at the Haemophilia Centre at the

Manchester Royal Infirmary. He was treated with Cryoprecipitate initially and then with Factor VIII (FVIII) concentrate.

5. **GRO-B** and I met and formed a relationship in 2009 and we married in 2015. **GRO-B** was a very private man. I did not know that he had haemophilia until I saw him with a needle and asked him 'why?' He had FVIII treatment on a prophylaxis basis three times each week. Because of the marks left by the needle, he did not like wearing short sleeved shirts and T shirts. He wanted to be treated as normal and for people not to know he had haemophilia. I did not know that he was co-infected with HIV and HCV until last year. He was too scared to tell me, fearing that I would leave him if he told me the truth. I loved him. It made no difference to me.

Section 3. Other Infections

6. **GRO-B** was also advised that he might be infected with vCJD. He used the words 'Mad Cows Disease' but was subsequently told 'No', he had not been exposed to that risk after all.

Section 4. Consent

7. I do not believe **GRO-B** to have consented to being tested for infection. He told me that after finding out about it at hospital (in his twenties) that he was left in utter shock. He couldn't deal with it and 'hit the beer' to try and cope.

Section 5. Impact of the Infection

8. **GRO-B** was in very poor health controlled with a cocktail of all different tablets. He had liver damage through being infected with HCV.
9. **GRO-B**'s first attempt at clearing HCV was unsuccessful. The side effects were apparently awful, leaving him with chronic depression and confusion. He told

me that he found himself picking bits off the carpet and being unsure as to why he was doing it. He was left with chronic fatigue that remained with him. He was so tired all the time that he sometimes didn't get up until 8pm or 9pm. We would go out together in the car in the evenings, making quality time for each other then.

10. **GRO-B** was a great character, always very funny and up for a joke but he lacked confidence and didn't like to mix with anyone much other than me. He was frightened I would find out that he was co-infected. He explained away his liver problems and fatigue by telling me that he had (at one time) been given the wrong tablets and that the tablets he had taken had damaged his liver.

11. **GRO-B** and I were inseparable, and I went to all his hospital appointments with him, but he left me to wait for him in the corridor/waiting area whilst he was in for his hepatology appointments (with Dr Prince and Dr Ash). He wanted to protect me and was scared of losing me.

12. We married in 2015 and it was around that time **GRO-B** had successful HCV clearing treatment. **GRO-B** hid everything away from me, telling me that he needed 'space' (because of likely side effects) to take tablets to treat cancer cells on his liver'. I remember the call he took from Sister Esther at Manchester with the good news. **GRO-B** confirmed to me (last year) that the 'good news' she had given him was in fact that the HCV infection was no longer detectable.

13. **GRO-B** had so many serious health issues through having HCV (and HIV). He had Portal Hypertension caused by cirrhosis, Pulmonary Hypertension (diagnosed at Sheffield) and a damaged spleen.

14. I called the ambulance out to him on numerous occasions because of variceal bleeding. He would go into the toilet to be sick and it was scary to see his blood everywhere. It was a blood bath, like something from a horror film. I would

quickly give him his medical injections whilst waiting for the ambulance to turn up. I can't imagine how **GRO-B** must have felt dealing with it all for so long.

15. **GRO-B** told me he was co-infected with HIV and HCV last year after he became unwell during the night with chest pains. I demanded to know what was going on after **GRO-B** hung up on a 111 doctor and told me not to talk to him if he rang back. He told me the truth then because he said he was ready to and because he didn't want me to hear about it from anyone else.

16. **GRO-B** had mood swings and suffered with social anxiety. He was only truly confident when he had a drink (and he abstained from alcohol entirely in his final six months). When he had an endoscopy in 2007/2008, he was allocated his own instrument, not to be used on anyone else. It made him feel dirty. **GRO-B** did not have a dentist because of a bad experience he had in childhood. When he needed one and was in a lot of pain with his teeth, we couldn't find one in our area prepared to treat him. I was appalled because there was one straight across the road from us. He was so unbelievably happy when I finally found him a dentist. It was heart breaking to see him in so much pain before we found one. **GRO-B** went through so much psychological torment. He was so scared that I would leave him or that people would treat him badly if they knew the truth of how sick he was. **GRO-B** told me that he would be treated as a leper in death and would not be embalmed as he was deemed 'highly infectious'.

17. When **GRO-B** told me he had HIV, he insisted that I had an HIV test too. Apparently, the haematology nurses had gone mad at him when he told them he was getting married, insisting he told me. At that time, and fearful of losing me, he did not want me to know anything about it. He was worried sick on the way to the hospital for my test. He was shaking with fear. As I suspected (because I had googled/researched all the information) my test result was a negative one.

18. GRO-B would always say to me 'I will break your heart one day'. He also used to say 'Keep me away from hospitals. If I go in, I won't come out.' Despite his poor health, I didn't expect to lose GRO-B so suddenly. GRO-B had a fall at a friend's house. I was actually waiting for a call from GRO-B for me to go and collect him when his son knocked on the door with news of the accident. He had sustained a bleed on the brain and was on life support for a week before he died through encephalopathy impacting on his kidney, lung and heart function. The cause of death was multiple organ failure, predominantly GRO-B's liver.

19. Before his death GRO-B was actively looking for bungalows for us to live at by the seaside in GRO-B and the surrounding area. We were robbed of it all. I didn't get to say goodbye to GRO-B. We had such a wonderful Wedding and honeymoon in GRO-B, saved up for by GRO-B. We celebrated our wedding anniversary each year in GRO-B where GRO-B could truly be himself. It was also difficult because if anything happened to him there, he had no insurance cover. He always insisted we had new clothes to go. We had breaks away in Blackpool too. We had special memories and the promise of so many good times ahead of us.

20. It is all still so raw to me and I can't get my head around any of it. Before GRO-B's death he was following the Infected Blood Inquiry on the live stream facility and made me promise that if anything happened, I would 'fight this' for this.

21. GRO-B was a big-hearted kind person who would help anyone out. I am now on antidepressants and anxiety tablets as I not only lost my husband I lost my best friend.

Section 6. Treatment/care/support

22. **GRO-B** hid his HIV medication at this sister's house at first. He was taking Retrovir and Abatavir tablets before he died, two white and one blue tablet.

Section 7. Financial Assistance

23. **GRO-B** received a payment from the MacFarlane Trust and Stage 1 and Stage 2 ex gratia payments from the Skipton Fund.

Anonymity

24. I do wish to remain anonymous and I understand that this redacted Statement will be disclosed for publication to the Inquiry.

Statement of Truth

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

Signed..... **GRO-B**

Dated..... 18.12.2020