

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2951001

Exhibits: 0

Dated: April 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 and I live at GRO-B
GRO-B I was born on GRO-B I am married and I have
GRO-B sons. I am a GRO-B and I analyse blood in GRO-B
GRO-B and previously GRO-B

2. I provide this witness statement in response to a request under Rule 9 of the
Inquiry Rules 2006 and I am aware that my husband, GRO-B
GRO-B also intends to provide a statement to the inquiry.

3. I am providing this statement without access to all my husband's medical
records.

Section 2. How infected

4. I am providing this statement on behalf of my husband, GRO-B
GRO-B known as GRO-B who was infected with Hepatitis C from
contaminated blood products.

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5. He was diagnosed with severe Haemophilia A when he was between [GRO-B] and [GRO-B] years old. He lived in [GRO-B] until he was [GRO-B] years old and had no medical treatment there for his Haemophilia.
6. He moved to the UK in [GRO-B] and was registered at [GRO-B] Haemophilia Centre where he started taking Factor VIII. He believes that he was infected around this period when he had a severe bleed in his leg.
7. The hospitals in which my husband was treated were [GRO-B] from [GRO-B] till now, under varying consultants including [GRO-B] [GRO-B] then [GRO-B] for Hepatitis C mainly from 2009 until now, under [GRO-B] and [GRO-B] in 1995 for a liver biopsy; and [GRO-B] in [GRO-B] after a car accident.
8. No information was given to him about having this Factor VIII treatment.
9. He was told he was infected with Hepatitis C in June 1992 in a letter from [GRO-B] [GRO-B] of [GRO-B].
10. I was trained at [GRO-B] to give my husband emergency injections; however, he always goes to hospital for his Factor VIII it as he hates needles.
11. The information as to how my husband was affected has been covered in more depth in his statement to the Inquiry.

Section 3. Other Infections

12. I believe my husband received a letter stating that he could potentially have been exposed to the vCJD virus.

Section 4. Consent

13. I do not know if my husband was ever tested or treated without his consent or knowledge.

14. Whenever I was at my husband's appointments, they explained to me about any new treatments for hepatitis C. I was always there before they started any new treatment.

Section 5. Impact of the Infection

15. My husband told me that he was shocked upon seeing the letter in 1992 informing him that he had been infected with hepatitis C; he did not understand what they were talking about and so became very worried, causing him to struggle to eat.

16. When I met GRO-B he told me straight away about his hepatitis C infection. My GRO-B all studied together so we knew each other. GRO-B wanted to tell me straight away before anything began between us, that he had Haemophilia and hepatitis C. I agreed to marry him as he was honest and I understood all his conditions. I wanted to support him and so we got married in GRO-B

17. In total GRO-B had 4 treatments for hepatitis C. Before we met he had a failed Interferon monotherapy in 1996 which stopped half way due to him constantly suffering from headaches, vomiting, and insomnia. He was told it was eating his white blood cells and drastically dropped his red cells which is why he became anaemic and suffered from those symptoms.

18. In 2008 in GRO-B he had a treatment of Interferon and Ribavirin, but he stopped after about 3 months due to neutropenia. He suffered from many of the same symptoms as before, including losing a lot of weight, headaches, insomnia, turning pale, and becoming very angry. Our first son was only GRO-B months old and so this was very difficult to manage as there was no one to support me with our child and dealing with GRO-B

19. In 2011 he was referred to GRO-B as GRO-B said they could not cope with any complications and GRO-B had a specialist team. Again his treatment was the same as 2008, namely Interferon and Ribavirin. He

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suffered the same side effects as in 2008 and he was also just constantly angry and really suffered from personality and mood changes, however, this time it was more intense as he took the treatment for 5 months.

20. Also during this 2011 treatment, GRO-B suffered many complications. His haemoglobin levels dropped and he had to have about 3 or 4 blood transfusions at least at GRO-B. He also lost a lot of hair as a result of these treatments and he had to take our son with him as he had no one to look after him as I was at work.

21. By the end of 2015, GRO-B was fatigued and regularly had night sweats and a non stop cough for months on end. He got respiratory infections as he was more vulnerable to them. He struggled to sleep and had a fever regularly. All this was difficult to deal with and he was constantly stressed.

22. In January 2016, he took the treatment called Harvoni for GRO-B months. This also gave him side effects including headaches, becoming very weak, a loss of appetite and anger issues; however, all the side effects were better than in 2011. He completed the treatment. It worked and cleared the Hepatitis C virus.

23. GRO-B seemed to lose interest, drive and enthusiasm to do anything while on these treatments, which was very unlike him. I would not let him be negative though; I am an optimist and I always believed that a treatment will come out that will work. I was always positive and I tried to make sure GRO-B was too. I try not to take notice of negativity.

24. In GRO-B just before GRO-B started his treatment, my father passed away after being in hospital in a coma GRO-B. Throughout this year I therefore had to travel to GRO-B multiple times, being the eldest daughter and a lot of my trips were on very short notice. This was a very stressful time for me and I found it very hard to cope with this on top of looking after GRO-B and our son. I have a very young family and got no help from anyone. I struggled a lot to keep everything together.

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25. In 2011 [GRO-B] did not have a good reaction to the treatment and so I was taking sick notes to his workplace for a while when he did not have the strength to go to work.
26. [GRO-B] Harvoni treatment was delayed for 2 years from 2014 when we found out about it, to 2016. We were told it was because NICE had not approved it. We were referred for a trial in [GRO-B] in the meantime, however, nothing ever materialised from this.
27. [GRO-B] had to have all his dental work done at [GRO-B] until very recently.
28. [GRO-B] had severe side effects and sometimes struggled to even get up, but I always helped him and encouraged him to try new treatments. There was a period where he did not leave the house for 5 months so I started working part-time to look after him. I told my work that I had to look after my son, I never told them about my husband as I did not want to tell them about his infection.
29. [GRO-B] started to step back from his social and family life since his infection and he would always make excuses to avoid them as he did not want to tell them or let them know of his condition.
30. [GRO-B] infection had a significant impact on his work and he suffered from discrimination. He was effectively pushed out of his job by his managers, even when they knew what he was going through. He was forced to change departments and suffered substantial stress and trouble sleeping from all of this.
31. In September 2015 [GRO-B] went for a fibroscan and was told his liver was in a very bad state, and he was on the verge of cirrhosis. This was a very dangerous stage and so he required frequent blood tests to monitor his condition.

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32. I did not tell my family about GRO-B conditions or treatments because I did not want to worry them. I did not see it doing anyone any good to just have more people worrying and asking questions about GRO-B. Only recently I told one of my brothers and my mother and I now am starting to tell the rest of the family about what I went through. I explain that everything is all clear now. I have still only told a very few close friends until now.
33. I even used to play down symptoms that GRO-B was experiencing to help him not to worry. Even when doctors would explain things to him he would not understand, but because of my GRO-B I knew what they were saying, however, I played it down when I would relay the information on to GRO-B. I wanted to keep him as positive as possible.
34. I was effectively a carer for GRO-B for a few years, especially during his treatments and had to call in sick from work many times; however, I could not tell them why. I had to deal with it all myself and never had anyone to talk to.
35. Our children always had to be left with friends when we had problems or appointments. This was of course regular and so I believe it did affect them as we were often leaving them with different people as we had no other choice.
36. GRO-B used to take the children out and about and to their friends parties but after GRO-B became ill, they all suffered as GRO-B could not take them anymore. This was hard on the kids and they struggled.
37. I had to be careful as I could not leave my job as otherwise I would lose my
GRO-B
GRO-B I worked my way up in my profession after doing a GRO-B
GRO-B in
which I received 1st class honours. I also studied GRO-B All
this was very hard but I worked hard to get to where I am today.
38. I was working full time originally, then I went part time during 2011 when GRO-B had his treatment, then in or around August 2011 I went back to full

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time. I stayed in full time work and then went on maternity leave in [GRO-B] before became part time again after my child was older.

39. We went for IVF treatment from 2002 to 2004. We tried twice in England and it didn't work. Then we went to [GRO-B] for the IVF treatment in 2006 and it was successful and we had a child in December 2007. I had a total of 5 treatments of IVF and I believe that the others failed due to the significant stress I was under complicating things. Our other son was born in [GRO-B] and this was a natural birth.

40. Most of [GRO-B] life has been difficult. He never had the [GRO-B] that I did and so he did not fully understand the implications when he was told. He had a terminal illness and he naturally took it badly. He was told that his liver could go bad, but he would not be given a liver transplant, and was also at risk of liver cancer. These were difficult things to hear, which is why I would play things down to him. He is a worrier and so I would only give him relevant information.

41. The NHS always gives the worst case scenario and it is not necessary, as it worries people which can just lead to more problems and complications than the original issue.

42. I always had to push the NHS to make sure they explained everything properly to [GRO-B] so that he understood, and not just worry more after an appointment due to not comprehending what he was being told. If I did not have the medical knowledge that I do, then it would have been a lot worse. I was able to help manage it better.

43. Only [GRO-B] who died last year, and [GRO-B] were very good and explained things properly. [GRO-B] was also very good and she gave [GRO-B] injections for about [GRO-B] years before retiring last year.

Section 6. Treatment/care/support

44. My husband never had, nor was offered, any counselling or support.

45. I was also offered no counselling or support and had to deal with everything on my own.

Section 7. Financial Assistance

46. I believe my husband received a lump sum payment from the Skipton Fund of £20,000 in October 2004.

47. We now get a £1,500 payment monthly from EBISS. This started in 2018. They rejected us first but then reviewed it and we started to receive payments. We are not eligible for a top up family payment as our income is more than £19,000 a year.

Section 8. Other Issues

48. I am a dual citizen so I had an easy route to GRO-B and both our families are there. They always wanted and requested us to come and settle there. I especially always wanted to go back to GRO-B but we were blocked from doing so due to my husband's infection and it is now too late with our circumstances.

Anonymity

49. I would like my statement to be anonymous.

50. I would like to provide oral evidence to the Inquiry, provided it can be anonymous.

Statement of Truth

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

Signed. GRO-B

Dated. 07. 05. 2019