

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1581001

Exhibits: 0

Dated: 16th January 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 My date of birth is the GRO-B
and I live at GRO-B I married my
husband, GRO-B we had known each
other since GRO-B He past away on the GRO-B at the age of GRO-B I
am employed as a GRO-B although I have been on sick leave since my
husband died.

2. This witness statement has been prepared with the benefit of partial access to
my husband's medical records.

Section 2. How affected

3. My husband was born on the GRO-B and worked as a GRO-B He was
diagnosed with mild Haemophilia A when he was a child; however, I am not sure

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when exactly. I recall being told by him that he used to receive different blood products to treat his Haemophilia, including plasma concentrates and Factor VIII.

4. I presume that he was treated with Factor VIII and other blood products, from the time he was diagnosed with Haemophilia.
5. He did not get many severe bleeds, his Haemophilia mainly caused him to suffer internal swelling to his joints and tissues. As a child he would try to keep away from things that could potentially cause him injuries such as riding a bike or playing football.
6. From the [GRO-B] he was treated at the Haemophilia Centre at [GRO-B]
[GRO-B] When he went to study [GRO-B] at
[GRO-B] he
was treated by [GRO-B] Consultant Haematologist at the Haematology
Centre.
7. While I have no direct knowledge that he or his parents were given information or advice about the risk of receiving blood products, [GRO-B] he might have known of the risks, or at least undertook research so as he had some knowledge or at least he may have tried to reassure himself by undertaking research. However, I do not believe that if he had any knowledge of such risks he would have agreed to the treatment he received.
8. As a result of being treated with blood products, my husband contracted Hepatitis C (HCV).
9. My husband did not speak often of his condition as he found it very difficult. In the early 1980's whilst he was at [GRO-B] he needed Factor VIII treatment at [GRO-B]

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10. In [GRO-B] my husband was admitted to [GRO-B] with abdominal pains, a provisional diagnosis of intramesenteric bleed was made. He was treated with Factor VIII. It is my understanding that prior to that he was treated with plasma concentrates. My husband strongly believed and told me that the doctor who treated him at [GRO-B] knew or ought to have known the risks of potential infection of the blood product given to him.

11. I recently wrote for my husband's medical records and amongst them I found a letter dated [GRO-B] from [GRO-B] Consultant Haematologist to [GRO-B]
[GRO-B] This letter refers to his treatment with Factor VIII in [GRO-B] The details of the product given were not available in his notes because apparently the data book at the Haemophilia Centre only went back to 1982. Therefore he could not say for sure what product he would have had. What I fail to understand is that if my husband received Factor VIII in [GRO-B] and the data book was held until [GRO-B] why the records of this treatment he received are not available. My husband believed that records were deliberately destroyed.

12. I believe that my husband found out about his condition in [GRO-B] aged about [GRO-B] when he was diagnosed with diabetes. His doctor at the Haemophilia Centre discussed the possibility of him being infected and the appropriate tests were undertaken which were positive.

13. At the meeting where he was told of his condition he was given a leaflet stating: "You have been informed today that you have Hepatitis C"; however, I am not sure whether he was given more in-depth information. The leaflet included some information, such as how the virus could be transmitted. [GRO-B]
[GRO-B]

14. I do not know whether the information given to him was adequate. [GRO-B]
[GRO-B]

GRO-B

GRO-B

Section 3. Other Infections

15. I am not sure whether my husband received any other infections as a result of the treatment he received, I believe it was only HCV.

Section 4. Consent

16. I have no knowledge as to whether my husband was treated or tested without his knowledge, or consent, or without being given adequate or full information or for the purpose of research.

GRO-B

GRO-B

Section 5. Impact

17. I know that the diagnosis of HCV was a shock for my husband.

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He was

very ambitious and he truly enjoyed his job, he was an extremely talented and caring. he tried to live his life as normal as possible following the diagnosis. He was also married with a young family.

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who he had to support.

18. The diagnosis with HCV caused my husband low mood and depression.

19. Further, he explained to me that his HCV caused him a lot of stress in relation to his job as he was afraid that people would find out about it and. but also that people would not be willing to work with him anymore because of the stigma attached to HCV.

GRO-B

GRO-B

20. He was reluctant to start any treatment because of the stigma and the side-effects. However, around the time he was diagnosed with HCV, gall-bladder polyps were found but due to the infection a decision was

GRO-B

made not to operate and the condition was monitored. However by [GRO-B] he decided to proceed with the treatment for HCV even though he knew the chances of success were small, he regarded it as his only hope.

21. The treatment consisted of Pegylated Interferon and Ribavirin but unfortunately the side-effects were severe. These included depression, extreme fatigue and loss of energy, which led to loss of motivation to do anything, memory loss, inability to concentrate, anxiety, difficulty to think clearly, sweats, muscle pain poor diabetic control, a cough and significant loss of weight.

22. But despite the side-effects of the treatment he continued to work for five months. However, when the side-effects became severe early on in the treatment they began to have a serious impact on his ability to continue to perform his job.

23. [GRO-B]
[GRO-B] Subsequently his ex-wife insisted he consult his GP and as a result he was signed off work on the [GRO-B]. Two weeks later tests showed there had been little benefit and treatment for HCV ceased.

24. The sick leave caused him a lot of problems at [GRO-B]
[GRO-B] Then rapidly after being placed on sick leave [GRO-B]
[GRO-B]

25. The severity of the side-effects also affected his family life, as he and his ex-wife began to experience marital problems and his wife subsequently sought a [GRO-B] which ended up being [GRO-B] and led my husband being [GRO-B]

26. He attempted to return to work [GRO-B] but he soon realised that he was not

able to function in his profession. GRO-B concluded after his assessment that it 'would be GRO-B to attempt to work GRO-B and that his performance would be 'unlikely to meet the GRO-B GRO-B

27. The application process for early retirement proved to be challenging. There were many questions asking about the nature of his illness, his life expectancy and whether he could still work, which made the process extremely difficult.

28. However, despite the reports on GRO-B inability to work, his application for early retirement was rejected.

29. In GRO-B D GRO-B provided a further report stating that 'Haemophilia and HCV do not, of themselves, make it impossible for GRO-B to work, but... the psychiatric illness...' caused directly by HCV does. It also stated that because of it my husband would be unlikely to be able to go back to work.

30. He eventually received early retirement on the grounds of ill health in GRO-B which affected his finances significantly.

31. It was a great shame that it happened, as he was GRO-B GRO-B GRO-B My husband's great potential for a successful career was cut short as he was forced to retire in his 40's and he felt cheated. He was quite angry with the NHS, he wanted his life back and blamed the NHS, he also felt very let down.

32. He lost everything because of his condition, his family, business, career, house, and he ended up having to move back to live with his parents.

33. When I first met my husband in about GRO-B I tried to help him to pick himself up,

as he was still severely depressed. He confessed that he had to move out from a tower block as his depression was so deep that he often had the urge to throw himself from his balcony. He was so scared of the temptation that he eventually decided to move out.

34. Whilst I believe that he improved over the time, I do not believe that he ever fully conquered his depression. He was seen by various psychiatrists, including GRO-B

GRO-B

35. My husband's interests in his hobbies which involved GRO-B
GRO-B also diminished. He began to see those things as a burden, rather than pleasure, as he did before.

36. During a routine scan in GRO-B the doctors discovered that my husband's HCV had caused Hepatocellular Carcinoma (HCC/liver cancer). The doctors originally wanted to perform a liver reduction surgery, after which they expected his liver to regenerate and re-grow. However, by the time they were ready to do it, they discovered that his liver had a lot more lesions and my husband could not have the operation.

37. A transplant was the only hope for him. However, as my husband's blood group was GRO-B it was very unlikely that they would find a donor.

38. GRO-B
GRO-B
GRO-B of part
of their liver. GRO-B and he
volunteered to donate part of his liver. GRO-B

39. The operation took place at the GRO-B under GRO-B
GRO-B Following the transplant, my husband started having a number of other

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health problems, he was constantly sick, he lost a lot of weight and needed to be fed through a nose tube.

40. The doctors hoped that my husband would have another 10 to 15 more years to live, as there was a new treatment for HCV and my husband was a suitable candidate for the treatment. However, it was discovered that he did not fit the criteria to have the treatment, as his liver was no longer damaged by HCV.
41. He had another MRI scan on the **GRO-B** and the doctors found that the cancer had returned. Nobody seemed to understand how it had happened. Unfortunately, he was not able to have another transplant, as his liver already had too many lesions.
42. My husband wanted to have Selective Internal Radiation Therapy (SIRT) for his liver cancer; however, this was not possible as after various tests it was shown that the treatment would pose too much risk to his life.
43. There were no other treatments available to my husband other than Chemotherapy, which he did not wish to receive. At that point, he was given a terminal diagnosis of between 2-4 months. Thankfully, he lived for over a year.
44. We married on the **GRO-B**, it had been our wish for a long time, but circumstances prevented it previously.
45. After finding out that there was nothing else that could be done to help my husband I had to take time off from my work as **GRO-B** in order to care for my husband in his final months.
46. My husband insisted on being treated at home and his dearest wish was to die at home in his bed. He was in terrible pain and finally he accepted to be put on an intravenous drug to help his pain. We all had to make the decision together

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because we all knew that it was the end of his life. My husband was a real fighter and tried to stay alive as long as he could to celebrate my birthday with me.

47. On my birthday, [GRO-B] all the family (his and mine) gathered together around our bed to celebrate my birthday with him and he gradually slipped into unconsciousness. His breathing became difficult and I rang the district nurse in total panic, the nurse came, gave him an injection and left. He died two hours later in our bed. I kissed him at [GRO-B] and he died soon after. His death was particularly traumatic because the doctor did not come to register his death until about [GRO-B] and he could not be moved until 9am. This was very traumatic for me because it took me a long time to go back to my bedroom as I kept having flashbacks about reliving the whole thing including seeing him dead in our bed. His death was registered on the [GRO-B]

48. Since my husband's death I have found it extremely difficult to cope, I returned to work for a few weeks; however, I started to [GRO-B] so much so that I was not able to continue to work. I feel overwhelmingly sad all the time and I cry a lot. I am currently still unable to work. I have been diagnosed by my doctor as suffering anxiety and depression and I am now taking anti-depressants. I had counselling but I need a further course and I am currently on a waiting list for further counselling.

49. My employers [GRO-B] have not been helpful and have declined to retire me on the grounds of ill health. As I am unable to return to work I have been forced to give notice to terminate my employment to my employers and take retirement. This means that I am suffering financially.

50. My husband did try to seek some answers about how he had become infected but he thought that some documents had 'gone missing' and he did not obtain the answers he sought. He got to the point where he chose to live life as best as he could and he tried not to dwell on the past.

51. My husband enjoyed travelling when he could but was never able to get travel insurance due to his HCV. Therefore, we took a huge risk whenever we travelled.

Section 6. Treatment/Care/Support

52. I do not believe that my husband had difficulties or obstacles in obtaining treatment. [REDACTED] GRO-B

[REDACTED] GRO-B He had around 3 or 4 treatments, and whenever he finished one course of treatment, a new one came out, which was offered to him. This included Telaprevir-based triple therapy in [REDACTED] GRO-B but that had to be stopped as he developed anaemia. Unfortunately, none of the treatments proved to be successful.

53. Overall, I do not think that my husband was ever denied any treatment; however, I am also not certain as to whether there was a better treatment out there, which could have been offered to him.

54. I recall that on one occasion my husband had some dentistry work done at a hospital department. Whilst he did receive treatment, he was dismissed from the service after the work was done. He refused to go to a dentist after that.

Section 7. Financial Assistance

55. I believe that my husband was paid stages 1 and 2 of the Skipton Fund; however, I am not certain.

56. I am also not sure how he found out about the fund, but it was likely to be through the Haemophilia Department at his hospital. I believe he probably received the payments in about 2006.

57. I am not sure how the application process went; however, I presume it was not particularly difficult as my husband was good with forms.

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57. The only preconditions imposed on my husband to be entitled to the payments that I can think of were that his condition had to reach a certain stage in order to be eligible.

58. I have also received one payment of £10,000 after my husband died. The process of application was straight forward. I was required to provide specific evidence, which I did. The only preconditions I can recall were first, I had to be married, and second, we had to be living together.

59. I am not sure whether I would have been informed about the Skipton fund if it was not for my husband. My husband found out about it when he was making his application and he informed me about it and told me to apply, in case anything happened to him.

Anonymity, disclosure and redaction

60. I confirm that I wish to have anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

61. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed

GRO-B

GRO-B

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January 2019
~~December 2018~~