Witness Name: GRO-B
Statement No: WITN1544001
Exhibits: 0
Dated: 29 March 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 My date of birth is GRO-B I have no children and I work as an end of life care GRO-B though I am currently off sick, due to depression and stress. I am married to GRO-B

2. I make this statement as the widow of GRO-B:H who was born on the GRO-B and who passed away on the GRO-B as a result of infections received through contaminated blood products. We met in GRO-B and were married on the GRO-B

3. This statement has been prepared without the benefit of access to my late husband's full medical records.

Section 2. How Affected

4. H had severe Haemophilia A with no clotting factor. He was diagnosed with Haemophilia when he was aged 2 as a result of regular and unexplained bruising. He had an older brother who also had regular and unexplained bruising and, so they were taken to GRO-B tests were undertaken and Haemophilia was diagnosed in both brothers.

5. H was treated at the GRO-B and he was under the care of GRO-B

6. He began treatment with Factor VIII when he was in his teens. Prior to that he was treated with blood transfusions.

7. He was about four years old when he suffered from a stomach bleed and was treated with blood transfusions, which probably saved his life. I am not sure as to the specific Factor VIII products which he was treated with at the beginning, but in the later years he was treated with Alpha and it was stored in a brown carton.

8. The Factor VIII products H was first treated with were American; later he was treated with English products. The batch numbers were not kept. We collected multiple bottles of Factor VIII from the hospital and then sent them back to the Haemophilia Centre. I believe it might have been Alpha; however, I am not sure H was treated with Factor VIII throughout his life until he died.

9. I do not believe that his parents were informed about the risks of using Factor VIII. Originally there were no leaflets or information on the bottles of the first batches of Factor VIII that came out. In the later years, there were information of the possible side-effects provided on the bottle or leaflets; however, this must have been around the time when it was required by law for medication to include information about the potential side-effects. This might have been in the 80s.

10. H was diagnosed with Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV) as a result of being treated with the contaminated blood products.

11. In approximately GRO-B I received a telephone call from him whilst I was at work. I worked for the GRO-B at the time. He sounded extremely distressed. He was not informed directly by the doctors; instead he was informed second-hand by his brother. His brother, received a telephone call from a Chinese doctor (however none of us could remember his name) saying that they were both infected. His brother then called H to inform him about it. Their mother then contacted GRO-B GRO-B who was shocked that this is how they found out. H then received a letter from the GRO-B in relation to his HIV infection. I specifically recall that the letter stated that the diagnosis did not mean he would develop Acquired Immune Deficiency Syndrome (AIDS). This gave us some hope. It was a shock to us both.

12. We did not know what HIV really meant; we only knew of it from what we had read in the newspapers.

13. Prior to receiving the letter he had been asked to attend hospital more regularly than usual for blood tests. Normally he was monitored every six months but the tests became more regular. H thought it was strange that he had to attend more regularly.

14. The letter provided no information in relation to how to manage or treat HIV. There was no mention of the risk of transmission. H was not provided with the opportunity to see or speak to somebody who might have been able to tell him more.

15. I do not consider the letter was an appropriate way to inform H of the infection, it did not give him an opportunity to ask questions or to express his fears and concerns or to go through what the virus meant. He should have been

seen by a doctor so as the doctor could explain the diagnosis. The way in which the hospital communicated such devastating news to H was very cold.

16. GRO-B found out about his HCV infection via a letter. I am not certain whether this letter came at the same time as the one about HIV or on a different occasion. I do recall that it was at around the same time.

17. I believe H could have had the infection since about the H

Section 3. Other Infections.

18. Around H H received a letter which stated he might have been exposed to Creutzfeldt-Jakob disease (CJD). He was devastated.

Section 4. Consent.

19. H was tested without his knowledge, and therefore impliedly without his consent. An example of this is the fact that he was not told he was being tested for HIV or HCV, he was tested under the umbrella of his usual tests.

20. I believe that H was tested without his knowledge as to the purpose of the tests. He had extra tests before and after his diagnosis; however, he was not made aware as to their purpose.

21. GRO-B a GRO-B told H that the reason for the extra tests was that his T-cells (a type of white blood cells) were not dropping as fast as the other haemophiliacs. But he was quite well at the time. This was after he received his diagnosis.

Section 5. Impact

22. From the time H was diagnosed with HIV and HCV, his mental health was never the same again. He was frightened and paranoid. His confidence drained.

23. He seemed to be more afraid of HIV than HCV. He had monthly blood tests and was told that if his T-cell count remained at 200, then he would not become ill. He became very fixated by this. When his T-cell fell to 100 it was almost the end of him, he had a breakdown and tried to kill himself.

24. He was totally paranoid, if he had a cold he would think he had AIDS, similarly if he had a sore throat: he would believe he had AIDS.

25. He also had a fixation about his weight. When he was ill with diarrhoea and he lost weight, he would think "*This is it, it's AIDS*". We bought new weighing scales, I tried to buy them on the heavier side as he used to weight himself multiple times during the day and if he weighed less, he would panic.

26. Physically, H did not start showing symptoms until the latter stages of his illness. He became jaundiced and he looked yellow. He suffered from shingles around his eyes and pneumonia. To add to everything else he managed to hit his head when he was in a taxi and he ended up looking like Elephant Man! The blow on the head started shingles. We went to see an emergency doctor who gave him medications. The doctor said that if H had not had the medications he would have lost his sight.

27. His immune system deteriorated and he suffered from sore throats or colds. Towards the end of his life, he believed he had a brain tumour but this was never officially diagnosed.

28. The last two years of his life were extremely difficult as he had HIV or AIDS related symptoms. However, apart from his mental condition and Haemophilia, H had done quite well for the previous 18 years. No one could see any HIV or AIDS symptoms until the last couple of years.

29. During the last 5 to 6 months of his life he could not stand, he suffered from swollen limbs, he just sat on the settee; he could not walk up the stairs and he suffered with an extreme lack of appetite which meant that he stopped eating. He had completely lost confidence in the GRO-B and did not want to be admitted there so his GP referred him to the GRO-B in GRO-B

30. I could no longer cope with his ill-health without help and needed respite. This was another reason why H was admitted to the GRO-B I could not deal with his walking needs, as he could not walk or stand. It was very difficult for me to clean him properly, as he was not able to do it himself at that point H did not want me to get anybody else involved in his care; however, I simply could not cope anymore.

31. He was seen by his GP, who originally advised him to go to GRO-B but due to the lack of trust and faith in the doctors H refused to go. His GP said that at GRO-B they do not like 'bed blocking'; however, since H was so poorly he would not be bed blocking H eventually agreed to go to GRO-B He was admitted there on the Saturday afternoon and he passed away on the Sunday morning.

32. H lived with the condition for 20 years. The treatment he was offered was antibiotics to keep pneumonia away but he refused the treatment as he thought it would make his immune system worse. He was also offered a cocktail of drugs but he refused again as he did not fancy the side-effects. I tried to encourage him when he was extremely ill and I said to him that he had nothing to lose. He thought they would do more harm than good and wondered why he should start at that time as he had done well till then. But I do not think he was thinking straight at the time.

33. GRO-B was a great mediator; H had known him for a long time. He tried to allay H fears but that may have been giving H false hope. However, I am not aware about how much the doctors knew or what choices they had at the time.

34. The impact on our private, family and social life was devastating. In the 1980's, nobody knew much about HIV and the newspapers spread a lot of negative information. A lot of H friends knew he was a haemophiliac and connected the dots which meant there were a lot of fall outs. Some friends stood by us which we were grateful for. Towards the end of GRO-B life, his mother supported us a lot and we dealt with his infections together. I am still friends with his mother now. My mum and dad, who are now getting on a bit, did not know what to do but were supportive. I used to hate it when they went away. I felt as if I was dealing with it on my own.

35. Our whole family were supportive, but people just did not know what to do or how to help, but just driving us to the GRO-B was help enough for example.

36. Our sex life went out of the window; we had to have protected sex. I had one test for HIV which was negative.

37. It has affected me mentally I felt that I was living with a ticking time bomb. I used to wake up in the morning worrying whether H was going to survive the day.

38. I lost a lot of weight which I have never regained. I was so worked up I could not eat. It would take me about an hour or two to chew a Ritz cracker!

39. I am not as cheery as I used to be. I had thought that the contaminated blood was a bad mistake; however, upon the Inquiry commencing last year it appears it is a lot more sinister. I am currently on antidepressants and I am off sick from work due to depression and stress. Also I started smoking and I continue to do so today.

40. Prior to his diagnosis H worked as a GRO-B Once he received the diagnosis of HIV and HCV he gave up his job because he became paranoid that the people around him would make him ill. He caught a cold and thought *"That is it, there is no point risking it"* and left. This meant that I worked full-time. Ultimately, the pressure of working and caring for H got to me and I stopped working to become H full time carer. However, after a while I felt that I needed to get myself away from home so I started working part-time for the local care home.

41. H was very good at cartoons and drawing. He was an extremely creative and a clever man. He would sit for hours sketching cartoons and taking the 'mick' out of what was going on in the world in his cartoons. He was a talented, charismatic and funny person. When his health deteriorated, he continued to draw which was his way of cutting off from reality and trying to deal with things. After his diagnosis, his cartoons became a lot darker and contained much more black humour; they showed how troubled his mind was.

42. I learnt to drive and we used to spend lovely times together exploring National Trust historical properties.

Section 6. Treatment/Care/Support

43. I do not believe that H experienced obstacles in accessing treatment but the only treatment he would take was Factor VIII. H refused to take antibiotics for pneumonia as he worried the side effects would be too bad and he was scared that it would make his T-cell count drop to below 200, which was the number he was fixated on until his death.

44. No counselling or psychological support was offered to H I believe that had he been offered such support, he would have been able to manage his fears and worries and he may not have felt as tormented.

45. No counselling was offered to me at the time although I received counselling through my GP's surgery after H passed away for about six months.

46. A doctor at the GRO-B found that H had an enlarged spleen; but did not know why adding in a passing "*it could be cancer*". But we did not hear anything else about it, that was what it was like at the hospital, we drove back home in tears. I do not recall the name of this doctor as we had only seen him on that one occasion and there was no follow-up appointment.

47. When H had to have a tooth out, he had to attend the dental department of the hospital due to his Haemophilia.

Section 7. Financial Assistance

48. During the first year after H died, I received a Widow's Allowance from the MacFarlane Trust. However, these payments stopped as they were means tested and I was working.

49. I have also received payments from the England Infected Blood Inquiry (EIBSS) but as my husband, GRO-B has a pension and I work, the payments also stopped.

50. H received a lump sum from the Skipton Fund. I believe this was the Stage 1 payment of £20,000. He then received another sum from the Skipton Fund a year before he passed away. I am unsure what the application process was for these payments, I was not involved.

51. I am not certain as to whether H had to sign any waiver letter; I certainly do not recall seeing him signing any waiver; however, he did receive some money.

52. We found out about the availability of financial assistance through one of the Haemophilia nurses and I believe that GRO-B helped him sort out the payments. In addition, H was involved with the Haemophilia Society, so he might have had received further information from them.

53. When I needed financial assistance to carry out car repairs to be able to travel to work, the MacFarlane Trust refused to give me a grant.

54. I remember both the MacFarlane Trust and the EIBSS were difficult to deal with, they are not sympathetic or understanding and I was usually in floods of tears by the time I had finished speaking to them.

Anonymity, disclosure and redaction

55. I confirm that I wish to apply to retain my anonymity and that I understand that my statement will be published and disclosed as part of the Inquiry.

56. I do not wish to give oral evidence.

Statement of Truth

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

Signe GRO-B

Dated: 29 March 2019