Witness Name: GRO-B
Statement No.: WITN2004001
Exhibits: 0
Dated: 25 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

A My name is GRO-B. I am the widow of GRO-B: H H was born on GRO-B and died on GRO-B. H was a haemophiliac who contracted HIV through the blood clotting product, Factorate.

B H and I met when he was 19 and I was 15. I was still at grammar school and we were boyfriend and girlfriend as we were in those days until we married in GRO-B I was 22 year old and he was 26 years old.

1. H was a haemophiliac. In those days they did not have classifications but I would say that he was a moderate haemophiliac. H s grandfather had been a haemophiliac and his mother was the carrier. His grandfather lived until he was in his 70s. He died of other causes; it was not the haemophilia that killed him.

2. H GRO-B. He was a lively, strong man with a very active brain. I also worked; GRO-B GRO-B

3. H and I lived in a beautiful, detached Edwardian house set in a magnificent walled garden in GRO-B. We had no children and had always had a good standard of living. We had two cars, went on nice holidays and a good social life.

4. GRO-B We envisaged this lifestyle continuing for the rest of our days, and it was his intention to start investing in a pension plan when he reached his 50th birthday.

<u>Section 2. How Affected</u>

5. From when I first knew H from time to time he would suffer from bleeds into his joints, these were called hemarthrosis.

6. As H got older, the hemarthrosis got worse and became quite debilitating. He started to have difficulty doing simple tasks such as tying his tie and things like that. When he suffered a bad one he would have to take to his bed to rest.

7. In all the years we were married until he contracted HIV he had only one admission to hospital, his haemophilia was successfully managed by ourselves and the Haemophilia Centre. The one admission to hospital was due to him suffering a hemarthrosis in his throat which was threatening his breathing.

8. H regularly attended the Haemophiliac Centre at the Royal Victoria Infirmary in Newcastle on Friday afternoons. The director of the Haemophiliac Centre was GRO-B and I recall the nurse was called GRO-B They were both great supports for many years. H had complete faith in them, they were very important to him.

9. When Factorate came along, we thought that it was going to be the wonder cure for his bleeding. I do not recall ever being told of the risk of infection of using the product. H never told me that he had been told that there was a risk. I believe he would have told me if he had known.

10. We were both instructed on how to inject the product into him. We used it diligently. When we travelled abroad on holiday we took it with us. We would stay in accommodation with its own fridge so that we could administer it when he needed it. I think we were injecting it every day as a prophylactic treatment.

11. We were so thankful for the Factorate. We thought that he would stop suffering from the debilitating hemarthrosis. The Factorate was meant to prevent them but over time it became clear that it did not.

12. After using Factorate for a while H s eyes started to go yellow and we thought that he was suffering from jaundice. He started to have breathing problems and suffered from Pneumocystis Carinii Pneumonia (PCP). He was admitted to Ward 25, Newcastle General Hospital, on at least three occasions when he started having these problems. H had always been very healthy and it was a real shock when he started to become ill and was admitted as this had not happened before.

13. We decided that it was not worth continuing with the injections as it seemed to be making him sicker and so at some point we stopped these. I cannot recall when he stopped the injections.

14. The year 1984 was the start of everything. It was this year that I learnt that H was suffering from HIV. H might have known before this, but if he did he had not told me and I do not think it had sunk in. He was in denial.

15. I recall that in 1984 GRO-B asked H in for a meeting and I went with him. I did not usually attend the meetings with GRO-B and so

I think we may have been forewarned that we were about to be given bad news. We were told that H had HIV and that his life expectancy was not good. This was a huge shock for both of us.

16. GRO-B did not explain what HIV was or what would happen. I recall that we knew more about it through the press than we ever knew about it from the hospital. I do not remember having a discussion about the infection coming from the Factorate. There was so much publicity, by the time H GRO-B, AIDS was being discussed widely. There were lots of press stories about the blood transfusion service and that people contracting HIV through their operations.

17. I recall that when we came out of that meeting we were both in tears, we were distraught. We went back to the car in the car park and sat and cried and hugged each other. It was awful.

18. I do not think that adequate information was provided to us. GRO-B gave us enough information for us to be very upset but I believe that was just because we were so shocked by the diagnosis. We were so distraught. We had to take so much in. I believe that we should have had an appointment with a third person present. What we were told was just devastating.

19. I felt betrayed by the staff at the Haemophiliac Centre because H and I had always regarded the Centre as a very important place in our lives. They were there to support us and advise. I believe the wider NHS knew and I feel terrible about that. The NHS had done this to us. They had ruined our lives.

20. The diagnosis was a huge shock. We stopped sexual intercourse as a precaution for me.

21. Looking back, he had been suffering from the related symptoms such as fatigue and the whites of his eyes being yellow, but we had not recognised these as significant and that he could be suffering from HIV.

Section 3. Infections

22. I was not aware that H suffered any other infections as a result of the contaminated blood products.

23. I understand that H's medical records confirm that he was HIV positive when tested in 1985 and died due to complications of the HIV infection.

24. I understand that the letter from Northern Region Haemophiliac service dated 17 January 2012 to Skipton states that on reviewing the batches of different plasma derived concentrate he would have been exposed to Hepatitis C virus.

25. H was not able to undergo the required biopsy to test for Hepatitis C as he was a haemophiliac.

Section 4. Consent

26. H had a very close doctor-patient relationship with GRO-B and his staff at the Haemophilia Centre. Those at the Haemophiliac Centre were very close. H had such trust in his doctor and what he was doing for him. The relationship was a long standing one.

27. I do not know if H was treated or tested without his knowledge or consent because I did not generally attend the appointments with him. It was not until his diagnosis that I attended the hospital with him. He had never inferred anything like that to me. I do not remember anything like that in the NHS: the doctor treated and the patient received it thankfully.

Section 5. Impact

28. When we found out that H was sick in 1984 he was in the terminal stages of HIV. His health deteriorated very quickly, but it took a long time for him to die. He endured huge suffering. It took GRO-B months from when H was diagnosed with AIDS in February 1986 to die; it was a terrible time for us. If he had not contracted HIV I believe he would have lived to be an old man like his grandfather.

29. H began to get thinner and thinner until he was emaciated. He was doubly incontinent and also became mentally impaired. He was a shadow of his former self.

30. One of the saddest things about watching H deteriorate was that his brain was quite affected. He was not always rational and was also in denial. He would not admit that he had HIV.

31. His ability to work was affected after he began taking the Factorate. He became unable to drive but for a while his brain was still sharp and so I would drive him to appointments. I gave up my employment as a GRO-B GRO-B in order to help him.

32. For some time he was able to function if I did the physical work and the basic aspects GRO-B for him, but then his brain became affected and it became impossible. H therefore sold his client list to another firm of GRO-B We had no income coming in after H stopped working and so this lump sum assisted us for a time.

33. His deterioration was part of the HIV. His mental capacity deteriorated quite rapidly. I believe that this was in the last year or so of his life.

34. In order to help us cope financially, we applied for Attendance Allowance and Mobility Allowance. These were both refused. We therefore had increasing money problems. We had pressure from creditors and bailiffs

whilst he was ill. With the help of the Haemophiliac Centre's social worker we appealed the benefits decision. We were successful in our appeal the first payment we claimed was received after he died.

35. H died on GRO-B. By the time he died we had terrible debts. H did not have life insurance as he was a haemophiliac. We had a big house, two cars and no money.

36. H was insolvent when he died. There were two executors of his will, I was one and the other was a solicitor. The solicitor advised that because we were the executors of the will we could become liable for his debts. We therefore renounced our executorship. This felt like a terrible thing to do, but I did not have a choice.

37. Even following his death his diagnosis of HIV impacted upon everything. For example, the undertakers insisted on a lead lined coffin.

38. H had a big funeral. Lots of people made donations which went to the Haemophiliac Society.

39. There then followed an awful period of trying to get work. I was too ill to work after H died. I had lost a lot of weight and was not in a good place. I had never been unemployed but could not work for 6 months after his death and had to sign onto the Dole and so lived on minimal income.

40. I sold our house and was able to buy a small modest house which I could afford to keep up by myself with what I had coming in.

41. A friend of ours was involved in the creating of a new charity GRO-B GRO-B I was offered the role of GRO-B and worked raising funds for a new lung research centre at GRO-B I started working at the charity and finally started to have an income.

42. I worked to support myself for several years before I was granted a pension by EIBISS. I was then able to stop working. I was in my 70s. I had no private pension and no other form of income so I had to work.

43. The period just after H 's death was a difficult and traumatic time. I was grieving and trying to adjust to my new life. For a long time afterwards I had nightmares about his death. I was diagnosed as clinically depressed and was on medication. I was lucky to have a very supportive GP who helped me get through those months and years.

44. Looking back, I do not believe H 's illness was dealt with properly. They were trying to cover it up but it grew and grew and they could not cover it up. I do not think they knew themselves what a monster it would be.

45. Nothing was ever communicated to us in writing. I cannot produce documentary evidence of what happened or letters from the Centre. Even H 's death certificate was not very explicit. I believe that the NHS knew an awful lot more about it which they did not tell us but I think they were just hoping it would go away.

46. I knew about the risk of passing it to others and I believe I learnt this from the press. I do not recall every being told this by medical professionals. I was tested as soon as H was tested and was tested again following H 's death when I started a sexual relationship with my second husband. I had not contracted HIV. I think I did not become contaminated because I had a very early hysterectomy (aged 32 for medical reasons).

47. There was such stigma around sufferers of the disease and H worried hugely about what people thought of him. The word 'AIDS' was

overpowering at that time. The stigma was horrendous. No one had any understanding of H's illness.

48. I was also affected by the stigma that attached to H's diagnosis. Before H died I was at my dentist for a regular check up, my dentist informed me that he did not want me as a patient anymore. There was no explanation given. I believe it was because he knew that H had been diagnosed with HIV.

49. There were all sorts of rumours going around about H's illness, GRO-B GRO-B. 'AIDS' was associated with homosexuals. In those days there was terrific stigma. We did not broadcast the fact that H was suffering from HIV, but people found out, it got around.

50. H and I had very good friends. Many of our friends supported and protected us but we also had others who dropped us and did not want to be associated with him or with me.

51. GRO-B

52. GRO-B

53. Following H's death his father was a broken man. H was his only child. They had always been very close.

54. In GRO-B I married again. It turned out to be an absolute disaster. GRO-B GRO-B I eventually left him when I

was 63 years old. I moved to a tiny apartment in a block of sheltered housing provided by a local charity.

55. I then rebuilt my life again. GRO-B GRO-B This was a useful period of working life in your 60s and 70s. I had a demanding job and was able to function again at a level. GRO-B

56. I took on a lot of volunteering roles. GRO-B GRO-B I have now met a lovely widower in his 80s. We do not live together but we go on holiday. He is very supportive of me and has helped me emotionally. He came with me to the preliminary hearings in London.

57. To this day I still have nightmares about the past. I still cry easily and hate talking about what happened. He died 32 years ago but I still get upset.

58. H and I had a lovely life together. I loved him very much. He died just before our silver wedding anniversary. Our life together was destroyed not by his haemophilia, but by the poisonous drugs that were administered to him by the NHS. This is where my bitterness lies.

59. I felt and still feel very strongly that someone should accept responsibility for what they did to me and to my husband. He could have lived with haemophilia, he died of AIDS.

Section 6. Treatment/Care/Support

60. Following his diagnosis he had several admissions to Ward 25 of the Newcastle General Hospital. After every admission he came out weaker.

61. One of the reasons for his frequent admissions to hospital was that the whites of his eyes had turned yellow and he had a persistent cough. I did not realise then the significance of it, nobody told me, nobody explained it was a symptom of HIV.

62. Ward 25 became known as the 'AIDS Ward'. It was where the homosexuals with AIDS were admitted. There was stigma attached to being a patient in Ward 25. All the patients were in individual rooms and there was barrier nursing.

63. I went into visit him in Ward 25 twice each day, at lunchtime and in the evening. I would bring tasty food with me from M&S to try to tempt him to eat.

64. The Ward 25 care was appalling. H could not eat the food they provided. He was starved. The Friday before he died, the evening meal was pizza and chips. He could not swallow. He did not have the strength to chew. He mouth was coated with thrush.

65. The night nurses would come in with double masks and double rubber gloves. He was meant to be turned on an hourly basis but they did not do that. They did not want to touch him or to turn him over. It was very distressing for me and his father to see H suffering so much.

66. I recall that two nights prior to his death he was hallucinating. He started instructing me and his father to do his bidding. GRO-B GRO-B It was devastating to see and to experience.

67. When H died he was under the care of the haematologist, GRO-B GRO-B H was being given pain relief during the day but during the night he was delirious with the pain. The night staff would refuse to give him anything because it had not been written up. I pleaded with the staff

but they refused. He had no pain relief. We sat with him through the night, it was horrendous. And then he died – it was tragic that he died in so much pain and dementia.

68. Following H's death the Haemophiliac Centre social worker was good to me. She arranged some remedial therapy for me which was helpful. I went to appointments with a lady who taught me how to breathe and how to relax.

Section 7. Financial Assistance

69. Following H's death, the Haemophiliac Society gave me a grant so that I could have a holiday.

70. The Haemophiliac Centre also contacted me about H's HIV. They got in touch with me a year or so after H died and told me about the Macfarlane Trust. They told me that I might get a grant through the Skipton Fund. With the help of staff at the hospital I applied for the grant and got a stage one payment. This was a considerable amount of money to me.

71. There was also a stage 2 payment but I had to prove that H had suffered Hepatitis C. This could not be proved because he had not had a liver biopsy. I understand that as he was a haemophiliac they could not take the biopsy as he would have bled to death. H's death certificate did not mention Hepatitis C. Therefore I could not get the payment from the charity.

72. I appealed against this refusal with some assistance from the Haemophiliac Centre at the Royal Victoria Infirmary. They supplied some additional information but the stage 2 payment was refused again.

73. I also instructed the solicitors GRO-B to act for me in a civil claim for compensation. I was successful and received a lump sum. I

had to pay own legal costs and it was a very stressful process but I was determined to fight for justice. Eventually it was settled and all legal fees paid. The compensation I received could never compensate for what had happened.

Statement of Truth

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

Signed GRO-B

Dated …25 February 2019….