

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2804001

Exhibits: 0

Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. GRO-B
 GRO-B I live at the above address with my husband,
 GRO-B: S father. I have three daughters and a son.

Section 2. How Affected

2. I am the mother of S GRO-B who was infected with a combination of HIV, Hepatitis C and Hepatitis B as a result of receiving contaminated blood products.
3. I understand that s will be giving a statement to the Inquiry.
4. This statement has been prepared without the benefit of access to s full medical records.
5. s has severe Haemophilia A 0%.

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6. [s] received Armour Factor VIII blood products from around 1977 onwards which resulted in his infections.
7. Until 1981, [s] attended the Oxford Haemophilia Centre and he was under the care of Dr Rizza and Dr Matthews.
8. From 1981 until approximately 1987, [s] attended Treloar's college, where he also received Factor VIII. He was treated by the Consultant who was in charge of the school. I don't recall his name, but it was Egyptian sounding.
9. As a child, [s] used to have Cryoprecipitate when he had a bleed. It used to take 4 adults to hold him down to administer the Cryoprecipitate. When Factor VIII became available we were led to believe that it was a "magic needle".
10. I was not given any information or advice about the risk of [s] being exposed to infection from blood products.
11. [s] was infected with a combination of HIV, Hepatitis C and Hepatitis B.
12. I do not know the precise date when [s] became infected. I also don't know whether he became infected when he was being treated at the Oxford Haemophilia Centre or at Treloar's college.
13. I recently found out that upon first contracting HIV the anecdotal evidence is that patients experience flu-like symptoms. I recall [s] being very unwell before he started at Treloar's.
14. In approximately July 1985, when [s] was 13 I found out that [s] was HIV positive. One day when he returned from Treloar's College his Haemorrhagic states card fell on the floor which stated he was HIV positive.
15. At that time I kept it a secret and I strongly hoped that a mistake had been made. Treloar's College had just broken up for the summer holidays and there was nobody I could speak to until September 1985.

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16. I didn't feel comfortable going to our GP about what I had seen.
17. [s] didn't know what I had seen written on his card at that point, as I didn't want to worry him, in case it was a mistake. He had a girlfriend who also attended Treloar's. When he telephoned her one day and her sister said that he couldn't speak to her, it transpired that her family knew that [s] had been infected a few months before we did, which was absolutely shocking. The girl's father had asked at the school whether any of the Haemophiliac children were infected as he was concerned about his daughter's safety.
18. When Treloar's reopened after the summer break I spoke to the Consultant in charge with the Egyptian sounding name straightaway. He confirmed [s] HIV infection. He said he was very sorry and that I shouldn't have found out in the way that I did. He said this in a very blunt way.
19. To my dismay, the Consultant at Treloar's didn't provide me with adequate information on how to manage [s] infection or details of how it could be transmitted. After [s] infection had been confirmed, we didn't even know whether we could drink out of the same cups as [s] We had to make our own judgments.
20. My husband and I felt completely numb once [s] infection was confirmed. We thought that [s] would die and we both dealt with this inwardly. I recall that my husband went to see [s] after we had spoken to the Consultant to tell him about his infection.
21. I learnt from [s] that before he found out about his infections Treloar's called about 20 children into the school hall one day. They were told about there being a disease in the United States (HIV), but not to worry about it as it wouldn't cross the ocean. Of these 20 children, only [s] and 1 other boy are still alive.
22. I absolutely believe that we should have been told about [s] infection earlier- as soon as his positive test result was known.

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23. It was appalling the way I found out about [s] HIV infection, from a card in his bag.
24. We were not given any advice by Treloar's about the risk of other's being infected by [s] HIV. I do not know whether [s] received advice in relation to transmission. I presume this may have been done at Treloar's, perhaps in sex education lessons.
25. As I had been a Registered nurse since [s] was 6 or 7 years old, once [s] HIV infection was confirmed I carried out research myself into his infection. What we learnt about HIV was what I found out myself, not from information provided by clinicians. There was no google in those days.
26. Once we knew about [s] infection we were very careful about being clean at home, but not to the point of being obsessive.
27. I had a vague idea of what HIV was a couple of years before we found out that [s] was infected after seeing an article in the paper about Haemophiliacs contracting HTLVIII from blood products. I was a little bit concerned, but I assumed [s] would be safe with the treatment he was receiving, as we had been led to believe that our children were being treated with the cleanest blood products in the world.
28. I recall that at the time the presumption was that these children infected with HIV would die and most of them did.
29. I don't know when [s] found out he had also been infected with Hepatitis C.
30. [s] told me that he had also contracted Hepatitis B at Treloar's.

Section 3. Other Infections

31. I am not aware of [s] receiving any other infections from blood products.

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Section 4. Consent.

32. We did not know that [s] was being tested for HIV before his diagnosis. Therefore, he was tested without our knowledge and therefore impliedly without our consent and without us being given any information about the testing.

33. I was never asked for permission or told about [s] participating in any medical trials or research. However, [s] was once injected with pig's blood, yet permission for this was never sought from my husband and I was never told. I only found this out from [s]

Section 5. Impact

34. Mentally, [s] shut down and kept himself to himself. He would fly out the room if my husband and I tried to discuss his infection with him. Recently, he told me that at the time he thought he was dying and that not talking about it was his way of coping with it.

35. Physically, [s] went through periods of looking unwell due to his Hepatitis. He appeared grey, gaunt and generally not thriving.

36. [s] was compliant with treatment but not anti-retroviral drugs.

37. In around 2000, [s] suffered with ophthalmic shingles, which is a condition which is opportunistic of AIDS. He was getting very deaf and had problems with his vision. He had to be treated in hospital with intravenous acyclovir for this. [s] liver also became fibrosed to a point of no return due to Hepatitis C.

38. When [s] got ophthalmic shingles at approximately 25 years old, it was a calling card for him to take his HIV medication. Once [s] decided to take his HIV treatment, he could instantly see and hear a lot better.

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39. [s] HIV is now well controlled and he has cleared his Hepatitis B and C infections.
40. [s] underwent three rounds of treatment to clear his Hepatitis C infection. When he underwent his first round of treatment, this failed badly. He looked like he was dying in front of our eyes. [s] liver was so bad that it was disintegrating and his urine was black. I had to call the doctor who was treating him, a Doctor Shapiro. She stopped the treatment immediately. She told [s] "we are not here to kill you, we are here to cure you". He had about 10 days of treatment.
41. The second treatment [s] had for Hepatitis C was successful in clearing the virus. The treatment took around 2 months.
42. [s] received Interferon treatment for his Hepatitis B which was also cleared.
43. [s] prognosis looks good on paper, but in reality it's not. It's a life gone.
44. Before [s] received his Hepatitis C treatment, he wrote a letter to David Cameron explaining the urgent need for him to have treatment and he explained the issues surrounding the long waiting list for treatment. However, [s] didn't receive a response to his letter. Had [s] received treatment for his Hepatitis C treatment straight after he was diagnosed, his liver would not have become fibrosed and he would not have been so unwell.
45. [s] dealt with the treatments inwardly. The main effect of the treatments I noticed was that [s] became emotionless.
46. I'm not aware of [s] infections impacting his treatment for any other conditions.
47. [s] spent a long time without a partner and lived with my husband and I. He married when he was 42, but has no children due to the risk of transmitting his infections.

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48. When [s] turned 18, he had what I can only describe as a "wild-time" which I think was in part due to his age and in part his way of coping with his infections.
49. I believe [s] infections have made him insular and distrusting of others.
50. The impact on me has been devastating. I was utterly distraught that [s] had been infected. I could not discuss it with anyone. I thought that my son was going to die and I couldn't ask for help when we first found out, as I didn't feel comfortable approaching our GP given the stigma associated with HIV at that time.
51. Emotionally, I was a wreck; but I was not allowed to show it because people would question it. My husband and I could not talk to each other about it or comfort each other. We did not know how to deal with it ourselves or what to do. Today, it is different and we support each other.
52. We kept [s] infection a secret and we only told our close family. However, nobody discussed it much. It was a difficult subject and it felt like if we didn't talk about it, it wasn't happening.
53. In terms of the stigma, I remember seeing the TV adverts about HIV and AIDS with my family which conveyed HIV as the plague. I remember sitting in silence and thinking "*get that advert off*". It was horrible. The stigma surrounding HIV was frightening.
54. When one of [s] friends passed away his father lost his job when people found out his son's death was HIV related. There was a lot of fear, firstly, in relation to the disease and secondly, of people finding out.
55. [s] once received help from a Solicitor in Northampton with financial matters. The Solicitor told [s] that none of his colleagues at the law firm could find out that he was acting for someone with HIV. Stigma was everywhere.

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56. When [s] older sisters found out about [s] infections, they were really supportive in a non-conversational way. They didn't discuss it with him unless he opened up to them about it. I do not think they were as fearful as I was.
57. I wanted Haemophilia out of the family, as it's such an awful disease. My daughter's son is also a Haemophiliac and I hope they never have to go through what [s] has.
58. My husband was a Sergeant Major in the Army and [s] is his only son. Although my husband never held the infections against [s] it felt like an insult to him that he might lose his only beloved son. When we first found out that [s] had been infected my husband couldn't talk about it, he was too upset. In those days HIV was seen as the plague and we didn't know how to deal with the fact that our son had it.
59. The human soul is quite resilient. It is coming up to 40 years since we found out that [s] had become infected from contaminated blood. I would like to live a reasonable life, but the diagnosis hangs over us all the time.
60. I am a strong person and have needed to be to deal with [s] infections. I think that [s] infections have made me harder.
61. [s] and I are incredibly close. I think we built a close bond as I used to give him his infusions at home. We never used to discuss HIV as it was too awful. However, we are now more able to discuss it.
62. I don't think [s] infections affected his education. My husband and I sent him to Treloar's to prevent his Haemophilia effecting his education. [s] did well in his exams and Treloar's also gave him extra tuition for his dyslexia.
63. [s] used to work for BT as an electrical engineer but he this gave up due to his joint pain. [s] did not disclose his infections to his employer.
64. Approximately 3 years ago, [s] completed a BA degree in History at the University of Northampton. He is currently studying a master's degree in English literature at the University of Hertfordshire.

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65. I have never told anybody at work about [s] infections and this remains the case today.

Section 6. Treatment/Care/Support

66. I recall that [s] infections did not impact on the treatment he received at the Oxford Haemophilia Centre.

67. Psychological support has never been offered to [s] or the rest of our family in relation to his infections.

Section 7. Financial Assistance

68. I don't recall how [s] found out that financial assistance was available to people infected by blood products.

69. I believe [s] received £20,000.00 from the McFarlane Trust.

70. I do not know anything about the process of applying for financial assistance and therefore cannot comment on whether there were any preconditions for being granted an award.

71. I don't know if [s] had any difficulties in applying for financial assistance.

72. I think the financial assistance [s] received was sufficient as he was single for many years. However, it was not a sum for him to be extravagant with. If he had had a wife or children when he received the award, the financial assistance would have been insufficient.

73. I have never received financial assistance from any of the Trusts or Funds.

74. I recall that [s] PIP payments were stopped at one point. However, [s] refused to accept this decision and appealed. At the appeal, the judge re-

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awarded the PIP payments to [S] and held that he should receive PIPs for the rest of his life.

Section 8. Other Issues

74. I have never been involved in any campaigning, mainly because this would have meant I would have had to identify [S] and I would never put him in a position which he did not feel comfortable being in.

75. Although I knew nothing about it until [S] was diagnosed with Haemophilia, I have a deficiency in Factor VIII which means that I have to receive Factor VIII blood products if I undergo any surgery. In around 1990, I underwent a hysterectomy and approximately 2 years later, I received a letter stating that I had been exposed to vCJD. I was told that there was no test available, but that I may have been infected.

76. [S] received the same letter saying that he had been exposed to vCJD.

77. Recently, I have had a knee replacement and I noticed that my medical notes and equipment were labelled as biohazardous.

Anonymity, disclosure and redaction

78. I wish to be anonymous.

79. I would be prepared to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.. [GRO-B]

Dated... 28.03.2019