

ANONYMOUS

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Witness Name: GRO-B

Statement No: WITN3880001

Exhibits: WITN3880002 - 005

Dated: 15th August 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 November 2019.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1944 and my address is GRO-B, London GRO-B. I am a pianist with an LTCL qualification in piano teaching and spent many years teaching pupils in the home. I retired about five years ago, but I still play for my own pleasure. I have been married to my husband GRO-B for over fifty years. We have three sons, one who lives in GRO-B near GRO-B, and the other two who live abroad.
2. I intend to speak about my sister GRO-B: S infection with Hepatitis C following a course of passive immunisation plasma treatment for HIV in the early 1990's. In particular, the nature of

her illness, how the illness affected her, the treatment she received, and the impact it had on my family and our lives together.

3. I can confirm that I am not legally represented and that I am happy for the Inquiry to assist with my statement.
4. I wish for my statement to remain anonymous to protect the memory of my sister and to protect her friends and family.

Section 2. How Affected

5. I was extremely close to my younger sister [S] throughout our childhood. We were both born in [GRO-B] during the war in 1944, and [S] two years later in 1946. [S] was like my twin, even though there were two years between us. We had two elder brothers and an elder sister, but our family was in two stages and there was an eight-year gap between my sister [GRO-B] and me.
6. [S] and I had much the same childhood. My father worked in the oil industry for Shell and we spent a great deal of time abroad. From [GRO-B] we moved to [GRO-B] then on to the [GRO-B] and then to a house by the sea in [GRO-B] where [S] and I spent six years of our childhood together. We went to French schools and both became fluent in French. Our father's final post was in [GRO-B] when I must have been around 11 years old. We spent a couple of years in [GRO-B] and then my father retired and we moved back to the UK in the early 1960's.
7. My sister and I went to boarding school in England and then went on to university. I went up to Cambridge to study for a history degree in 1963, although I spent much of my time on choral singing and music, which was my great love. [GRO-B] and [S] went to Oxford, but the rest of our family went to Cambridge. [S] and I remained close, however after university [S] life started heading in a different direction to mine.

8. I met my husband [GRO-B] during my first week at Cambridge and we were married in 1966. I spent about a year working as a secretary at the [GRO-B] and we then went on to have three sons together. We lived in London for about five years while the boys were young and then moved to [GRO-B] in Kent near to [GRO-B] civil engineering work. After seven years we moved to [GRO-B] London. The boys were by then cathedral choristers at [GRO-B]. They moved back home to private school when they were 12 or 13.
9. While the boys were young I suffered from depression and migraine and did not take on a job. After the boys left home I studied for an LTCL Teaching Diploma and started teaching the piano in the home.
10. [S] and I were still very close while I was raising my children and we were both living in [GRO-B] London, but our lives were going in very different directions. I was a married woman with three young children, whereas [S] was free. We didn't see each other very often, but we kept in touch as much as possible. [S] was much loved as an aunt by my children and their cousins.
11. [S] was probably the most high-powered academic out of the five children in my family. She was very beautiful, bright, and social – she had everything! When [S] went to Oxford she had an interview to study Science but she told the interviewers that she wanted to study English. She was awarded a Scholarship, and later graduated with a first class degree and then continued her studies, obtaining a BPhil.
12. After university [S] got a job as a lecturer at the University of [GRO-B]. It was a wonderful job and very hard to get, but she gave it up because she didn't like teaching and wanted to be a writer. She didn't take up a full-time job again after this, but she wrote literary reviews for magazines such as the [GRO-B] and she also did some teaching for the Open University. She just wanted to write. [S] was an idealist and she was very bad at compromising with life. She

didn't seem to accept that most people wanting to pursue writing also had full-time jobs.

13. [S] had no money because she was hardly working, but at some point she bought a little house near [GRO-B] with financial help from the family. Our father died in 1972.

14. In 1984, [S] brought out her first novel [GRO-B]. It was a difficult read and was not the kind of book that would hit the bestsellers list. She had struggles with the publishers and I believe they went out of business in the end. She continued with her literary reviews, and then in around 1990 moved to [GRO-B] for some months to write her second book. This was also a difficult novel and was never published.

15. I could tell from the early 1990's, perhaps even the late 1980's, that [S] was looking unwell. However, [S] did not tell me about her HIV infection until around 1993. Soon after she told me herself that she had got Hepatitis C from a blood transfusion (plasma treatment). The information in this statement regarding [S] discovery of her infections was not known to me at the time. It was only from [S] later disclosure, and a small handful of medical papers left with her estate, that I was able to piece together how she came to be infected.

16. We have come to understand from a diary [S] kept that she was diagnosed with HIV in October 1988. [S] knew that she had HIV when she moved to [GRO-B] in around 1990 and must have been quite unwell at this point.

17. Our understanding is that [S] contracted HIV not from blood products, but from a partner. [S] never married but had a number of sexual partners. She was in a relationship with an American lecturer who was bisexual, for quite a long time and even moved to the United States to live with him for a period. He had wanted to marry [S] but she didn't want to. I later discovered letters about his male partner also contracting HIV. Her diary suggests that he was diagnosed with HIV

prior to her in 1986. She wondered whether she may have also been positive at that point as she was ill with glandular fever.

18. We always assumed that [S] had contracted HIV from her American partner, but her diary suggests she wasn't sure he had infected her. As we know she had a number of sexual partners, it is possible that she may have contracted it from someone else. [S] had a whole group of friends from the UK and the United States that were gay. A number of them succumbed to AIDS and many of them died during the last five years of [S] life.

19. As part of her treatment for HIV, [S] volunteered to take part in a trial of a new passive immunisation treatment. She was a very brave girl and was game to try anything. We found a leaflet about the trial dated November 1991 in some of the papers left in her estate (WITN3880002). The leaflet explains that plasma would be pooled from healthy donors with high CD4 counts and treated to make sure it was free from infectious viruses. It would then be given to HIV1-positive patients in monthly infusions. The purpose was to try and delay the onset of AIDS by several years.

20. The leaflet suggests that the trial was being run out of [GRO-B] Hospital, however I am not sure whether that was where [S] received the treatment. We found a letter dated 30 May 1993 from [S] to Dr [GRO-B] at [GRO-B] Hospital where she refers to passive hyper-immune therapy being offered to her in the near future (WITN3880003). However, [S] states in the letter that either the London Hospital or the Facts Centre would be preferable locations for her monthly treatment, as the travel to [GRO-B] Hospital was further. I assume that this was the same treatment as the passive immunisation treatment referred to in paragraph 19 above. In view of the date lag it may have been a second trial of the same plasma treatment.

21. [S] letter demonstrates that she was keeping abreast of international developments in HIV treatment and exploring all of her

options. She was very interested in all the medical details as she had the brain for it. She states: "Given that I will be seeing [GRO-B] on June 29th – and there is, of course, the Berlin Conference in the interim – I feel that I perhaps ought not to embark on anything new before then, so as to give me a chance to review what if any my options may be in the coming months. I imagine you will get in touch with me when the passive hyperimmune therapy is actually about to be available." She was very well-researched and was not going into treatment blindly.

22. [S] letter is signed with the name [GRO-B]. This is the false name that [S] used for all medical treatment in order to conceal her identity. The surname [GRO-B] came from her study and translation of a French literary work called [GRO-B] by [GRO-B]. This was published in 1980, and later republished as a Penguin Classic in 1983.

23. I have no knowledge of when [S] was diagnosed with Hepatitis C, nor how she was told about her diagnosis. However, we have a letter [S] received from Dr [GRO-B] in June 1994 which suggests she was diagnosed sometime before then (WITN3880004).

24. In the letter, Dr [GRO-B] states he hopes [S] is recovering from her "nasty liver problem" and goes on to discuss the controversy around how she may have become infected with Hepatitis C. He appears sceptical that her infection could have come from the passive immunisation plasma treatment as he states it is "meant to be treated sufficiently to be sure of destroying all viruses and transmission of the C virus should not occur if this process is done properly". Dr [GRO-B] also notes that none of the other recipients of the same plasma donations had gone on to develop Hepatitis C. He concludes: "I must admit I am not at all sure we will ever manage to prove one way or the other what was the cause of your liver infection".

25. Despite the doubts expressed by Dr [GRO-B] I believe the letter shows he is half accepting that the passive immunisation plasma treatment must

have given [S] Hepatitis C. I don't believe that [S] used drugs or drank excessively so there is no suggestion that [S] could have contracted Hepatitis C through intravenous drug use or alcohol abuse. However, we do know that she had many different sexual partners.

26. I have no knowledge of what [S] was told about her Hepatitis C infection and how to manage it. She was well-researched and I am sure she would have known about the risks of passing her infection onto others.

27. I had no idea what [S] was going through until around 1993. It was as if [S] had two lives. One life was her family life where she was a lovely daughter, sister and aunt, and then she had a second life with friends and dubious partners that we knew nothing about. My sister [GRO-B] and I could see that [S] was looking ill and, in the end, we sat her down and forced her to tell us what was going on. I think this was about 18 months before [S] died. [S] said she would tell us, but not at that moment.

28. On a later date [S] told me that she was HIV positive, and still later told me that she had got Hepatitis C from treatment for HIV. I recall she said something like "there's always a risk and it just so happened that some people got Hepatitis C from it". [S] told us not to tell my mother or the rest of the family, which was very difficult for us. My mother was well into her eighties at this point. [S] was very protective of her and didn't want to hurt her.

29. [GRO-B] and I were very careful with what we asked [S] about her diagnosis. We wanted her to enjoy the rest of her life. Once we knew about her diagnosis we did everything we could to help her, but she was still quite secretive.

Section 3. Other Infections

30. I do not have any knowledge of [S] contracting any infections other than Hepatitis C from the treatment she received for HIV.

Section 4. Consent

31. I am unable to comment on whether [S] was treated or tested without her knowledge or consent or without being given adequate information. [S] never discussed this with me.

32. As for [S] being tested or treated for the purposes of research, I have already mentioned [S] participation in the passive immunisation trial for her HIV infection. It is possible she may have participated in other trials in relation to her Hepatitis C infection as well. [S] would have been aware of, and would have consented to, any trials she participated in.

Section 5. Impact

33. From the time [S] told us about her diagnosis it was a downward spiral and [S] gradually started looking more and more ill. She was very beautiful, but she looked very pale, her hair had gone straggly, and she was very thin. I didn't particularly think of HIV when I saw her, but she did look very ill. During our final holiday at our cottage in Suffolk in 1994 [S] was coughing all night and had to get up a lot. I recall her worrying about disturbing us.

34. While it appears that [S] underwent some treatment at [GRO-B] Hospital for her HIV, she eventually ended up as a patient at Chelsea and Westminster Hospital. In terms of the treatment [S] received, I believe she was taking AZT in her final years for her HIV infection, in addition to another medication. I am not sure what the other medication was as [S] didn't tell me anything about her medications.

35. As for [S] Hepatitis C infection, I have no knowledge of the treatment she received, nor when this started, but I think she would have started treatment as soon as she was diagnosed. She would have gone off and researched everything and would have been willing to experiment different treatments. She was that kind of person.
36. [S] never mentioned anything about liver biopsies or fibro scans, although I think she was having liver investigations quite soon before she died. After [S] death, [GRO-B] husband [GRO-B] who is a doctor, was told by the doctors treating [S] that [S] had refused to have a biopsy.
37. One treatment that [S] received, I believe for her Hepatitis C infection, was blood transfusions for variceal bleeding. I recall [GRO-B] husband [GRO-B] explaining that [S] had issues with varices.
38. It was during one of these blood transfusions in [GRO-B] 1995 that [S] had a heart attack and died. Her death certificate states that the cause of death was congestive cardiac failure, chronic liver disease, and Hepatitis C infection (**WITN3880005**). I mentioned that [S] had HIV when her death was registered, but there is no acknowledgement of this on the death certificate. I am sure this is because she died from the Hepatitis C, not the HIV.
39. I found out later from one of the nurses on duty that there was another patient next door to [S] in emergency, and so the doctors were rushing between them. I am not sure whether [S] would have survived if this hadn't been the case.
40. The blood transfusion in [GRO-B] 1995 was administered to [S] under her false name [GRO-B] and so when she died the hospital had the difficult task of tracking down her next of kin. I think the hospital had [S] address and managed to find a letter from [GRO-B] on the desk at [S] house.

41. The hospital called GRO-B at around 10.30pm and GRO-B and her husband picked up my mother and me and drove to the Chelsea and Westminster Hospital. We didn't even know that S had been in hospital for a blood transfusion. She usually told us the bare minimum and did not want us to visit her in hospital. We found S in a cubicle lying peacefully. At some point we asked what we should do with S's possessions as we thought they may be contaminated, but the nurses said it was fine.
42. It is my view that if S hadn't contracted Hepatitis C she would still be alive today. There were new treatments coming out for HIV from 1996-97 and S was right on the cusp of that. She was taking AZT and hadn't yet developed full blown AIDS, so it is entirely possible that with new treatment she would have survived the HIV. The passive immunisation treatment was meant to treat her HIV and that's why she embarked on it, but instead it gave her Hepatitis C.
43. S Hepatitis C infection was a death sentence. It shortened her life and was such a waste. S could have been something really good. She had so much potential and there were so many things she wanted to do. Her diary mentioned all the things she longed to do if she could live longer, including getting more of her work published and playing the piano.
44. While S didn't have a lot of success with publication, she did write a lot for literary reviews and knew some of the big names in literature at the time. She was right on the edge of these literary circles because she hadn't experienced big success yet.
45. S was unusual and didn't fit a standard pattern. After she died her friends said they remembered her laugh and her personality. When she came into a room everyone would turn around and look. My mother always worried about S however. Her life was rocky, and my mother would always say there was a bad fairy at her cradle. She had 48

years, and she did have a good life with lots of travel and a small circle of devoted friends.

46. I don't think that [S] was the marrying type or wanted to have children, but I do think she wanted to be loved and needed the physical element of a relationship. She was very close with her American partner, and he wanted to marry her, but after living with him in the United States she walked away. She did remain in touch with him however, right until the end when he eventually died from AIDS. Her diary suggests that she never told him about her HIV infection. She could have told him, but she was so caring.

47. Once [S] was diagnosed with HIV, and then Hepatitis C, she felt she couldn't have a sexual partner and I think she must have been pretty unhappy. I do think she had a boyfriend at one stage, but when she told him about her infections he backed away.

48. [S] never mentioned anything about people labelling her or thinking she was an alcoholic because of her Hepatitis C infection. She used to tell people she had chronic fatigue and that was why she couldn't go to events. I don't think she shared much about her health problems with her friends. They may have known about her HIV and Hepatitis C right at the end, but I think she largely kept it to herself. It seemed from her friends' reactions at the funeral that they didn't know.

49. [S] death has had a huge impact on me. I was so close to [S] that her death was like losing my other half. I was the literary executor of [S] estate. [GRO-B] and I edited her diaries and more recently I went through all [S] literary papers. This was all incredibly painful for me. There are however a lot of great things to remember about [S]. On our last holiday in Suffolk we bought a little myrtle tree sapling which is now a healthy tree in our garden in London and reminds me of [S]. There is also an Italian pine at the cottage in Suffolk which [S] grew from seed.

50. In addition to the pain of losing [S] there is also the hurt that [S] didn't tell our family what she was going through. I don't know why she didn't tell us. When I had cancer in around 1991, I remember [S] coming into the hospital to see me and giving me all of her sympathy. That whole time she would have been holding in everything that was going on with her. It is really as if she had a second life that we knew nothing about.

51. Once [GRO-B] and I found out about [S] diagnosis, it was incredibly uncomfortable keeping it from our mother and the rest of the family. We felt we had to respect [S] wishes, as it would have destroyed whatever relationship we had with [S] if we had told the rest of the family. It was awful for [GRO-B] and I. My husband [GRO-B] says it was like being told something earth shattering and just having to put it in a box and throw away the key.

52. [S] decision not to tell our mother was really misguided. She really should have told her, although I know her decision not to was out of love. Our mother didn't find out about [S] illness until we were called to go into the hospital on the night she died. It was an awful night and I can't remember exactly what we told her. I think we might have told her that [S] had HIV, and while she knew this was a blood disease I don't think she completely understood what it was. She was 88 at the time, and while she didn't have dementia, she was confused at times.

53. Our mother didn't talk much about [S] death but the pain for her was so great because she loved her children so strongly. She was always protective of [S] and had always worried about her because she hadn't done as well in life, and then the worst possible thing happened.

54. My brothers also didn't find out about [S] illness until the time of her death, and I think [GRO-B] and I slightly wanted to protect them from it. Our brothers had always been in and out of our lives with boarding school and living abroad, but they loved [S] dearly. At the time we told them that [S] had died from HIV. We didn't know much about contaminated

blood nor the fact it was the Hepatitis C that had caused [S] death. It was a while before we properly understood the distinction.

55. [S] got on very well with the younger children in our family and her death had a huge impact on them. She got on well with my first cousin's younger son, who was absolutely devastated. His wedding in England was probably the last social function [S] went to, and she had to bluff that she was fine when she wasn't.

56. [S] had been in a relationship with [GRO-B] while she was at Oxford. He didn't know anything about [S] illness and what she went through, but saw her funeral advertised in the paper. [GRO-B]
[GRO-B]
[GRO-B]
[GRO-B] Obviously he was upset by [S] death, but he didn't have to upset us further as well.

57. Our family was so close, and I have always remembered my mother saying "family comes first". To lose a member of the family so young is devastating. Out of the five children in my family I am now the only one left. My two elder brothers and my sister [GRO-B] all became ill and died within two or so years of each other. [GRO-B] death in 2016 was a particularly huge blow.

Section 6. Treatment/Care/Support

58. [S] never mentioned anything to me about facing difficulties in obtaining treatment, care and support in consequence of being infected with Hepatitis C, nor HIV for that matter. She never made any criticisms about the doctors that treated her. I also have no knowledge of whether she was ever denied dental treatment.

59. I do know that [S] was referred to one or two counselling places in relation to her HIV infection. I believe one of them was called The Lighthouse, and the other may have been Positive Women. She certainly found out what was available and would give things a try. She was very intelligent and I know she found the counsellors not very helpful.

60. I have no knowledge of whether [S] was offered counselling in relation to her Hepatitis C infection, but I suspect by this point she wouldn't have been keen on counselling.

Section 7. Financial Assistance

61. I am not aware of [S] having applied to any funds or trusts for financial support in relation to her Hepatitis C infection. I think she was in receipt of ordinary benefits from the Government, but I am not aware of anything extra that was specific to Hepatitis C.

62. [S] could have had a highflying job, but because she wanted to be a writer she had no salary and wasn't well off. I know that my mother helped her financially. [S] wrote a letter to [GRO-B] and I on one occasion saying she had no money and felt bad for taking money from my mother, but that it was the only thing she could do.

Section 8. Other Issues

63. My sister [S] was private both about her HIV status and her Hepatitis C infection, but she believed in telling people things and would have wanted to be a part of this Inquiry.

64. My purpose in sharing this statement is for the general good. I am not looking for money or anything else from the Inquiry, as there is nothing the Inquiry can do for me now. I hold the pain of my sister's death and no one can take that away. I just want [S] experience to be part of the Inquiry story.

65. The important thing for me is that this never happens again. It has affected so many people and never should have happened. When the Inquiry is concluded, I would like to see the report of the findings and recommendations.

Statement of Truth

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

Signed _____

GRO-B

Dated _____

15th August 2020

Exhibits

Exhibit No:	Description	Date
WITN3880002	Leaflet on trial of passive immunisation treatment, published by UK Directory of HIV/AIDS Treatments and Trials	November 1991
WITN3880003	Letter from [redacted] s [redacted] GRO-B to Dr [redacted] GRO-B [redacted] GRO-B Hospital) regarding availability of passive hyperimmune therapy	30 May 1993
WITN3880004	Letter from Dr [redacted] GRO-B [redacted] GRO-B Hospital) to [redacted] s [redacted] s regarding Hepatitis C infection	14 June 1994
WITN3880005	Death certificate of [redacted] s [redacted] s	17 March 1995