

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3854001

Exhibits: WITN3854002-015

Dated: January 2020

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 I live at GRO-B
GRO-B My date of birth is the GRO-B I married my
wife, GRO-B on the GRO-B We are the parents of GRO-B: S
GRO-B

2. I make this witness statement in relation to S who was
born on the GRO-B S has also provided a witness statement
to the Inquiry GRO-B

3.

GRO-B

4. This witness statement has been prepared without the benefit of access to my son's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. [S] was diagnosed with Haemophilia B also known as Christmas disease at the age of about [GRO-B]. Following a fall he was taken by my wife and I to the [GRO-B] and thence to the [GRO-B].
[GRO-B]
6. Haemophilia does not run in the family. [S] was the first to be diagnosed. We met with the doctors at the hospital to discuss the question of transmission of Factor IX (FIX) through genetic inheritance; it seems to be a genetic mutation. It just happened.
7. In essence Haemophilia B is a deficiency of the blood clotting factor, Factor IX (FIX). After this diagnosis [S] was under the care of doctors and nurses at the [GRO-B] and the Royal Manchester Children's Hospital (RMCH).
8. [S] has exhibited in his witness statement at paragraph 8 [GRO-B] letters which confirm his diagnosis with Haemophilia B. The letters also confirm that he was given blood transfusions and fresh plasma on 'various' occasions following admission to the [GRO-B] and on the [GRO-B].
[GRO-B] [S] was treated with FIX.
9. As soon as [S] was diagnosed with Haemophilia I was anxious to discover what I could about FIX deficiency and how best to ensure that, so far as possible, [S] life would not be unduly affected. I therefore undertook some research in the [GRO-B]. I exhibit at 'WITN3854002' notes I made in the library and an article 'Haemophilia Today' by C R Rizza and Rosemary Biggs, Oxford Haemophilia Centre, which I found in the library about Haemophilia.

10. I also wrote to Dr Rosemary Biggs about [S] Haemophilia and she replied to me, by letter, dated 12 February 1979. I also wrote to the University Hospital of Wales and Dr A L Bloom replied to me on the 13 February 1976. Both of the above letters are exhibited at 'WITN3854003'.

11. In addition to the blood transfusions referred to above, when we returned to our home in [GRO-B] from [GRO-] we were supplied with FIX concentrate in glass bottles and vials of sterile water and we were told to take them to our local hospital at [GRO-B]. We attended [GRO-B] and we were told that we could take [S] to the Children's ward at [GRO-B] at any time bypassing usual admission procedures. My wife took [S] to the ward on many occasions and I accompanied them sometimes. In due course we were taught how to treat [S] at home.

12. [S] started to self-administer the prescribed blood products from about the age of [GRO-B]. Prior to that my wife administered FIX, usually at home.

13. I became aware that there was a problem in the late 1970s in relation to blood products but the nature of the problem was not fully explained. I was pressing and trying to find out. It's difficult for me to nail it exactly. [S] statement at paragraph 13 correctly refers to the Haemophilia Society publication in February 1976 which describes the risk of 'hepatitis' arising from imported blood products. I also exhibit at 'WITN3854004' a copy of the Haemophilia Society publication, dated February 1976.

14. I was not directly told by the doctors of the risk involved with FIX. I had a general concern about infection from the blood products. However, I became aware of more specific potential risks of infection from blood products, as the issue of AIDS became a national issue in the early 1980s. I exhibit at 'WITN3854005' a leaflet published by the Government in 1983. This confirms that at that date the Government was aware that AIDS could be transmitted by blood products.

15. I exhibit at **'WITN3854006'** a letter dated 27 November 1984 from Dr Evans from the RMCH addressed to me, which sought to "put your mind at rest". Whilst I do not have my letter to which Dr Evans responded to I believe this quotation confirms that my wife and I were concerned about AIDS and that it had been communicated to the doctors. The letter from Dr Evans also states that "until recently, our main concern was with hepatitis". Significantly, it also states "we have checked his S liver function tests regularly and I am glad to say that the results have always been normal. However, you will be interested to know that his blood had the antibody for Hepatitis B (Hep B) and that it became positive sometime between March 1982 and October this year (1984)". Whilst S must have had Hep B, his blood was no longer infected. However, Dr Evans went on to say that "he may get other forms of hepatitis". The letter alludes to a new risk in respect of which S was to be tested.

16. I had GRO-B and since Dr Evans was always willing to discuss the concerns of my wife and I about the risk of infection through blood products, I was very pleased that he wrote to the Minister for Health on the 8 January 1985. I exhibit a copy of his letter and the memorandum he prepared at **'WITN3854007'**. The final paragraph of the letter states "there is also a risk from other infections". I draw attention to the last paragraph of the memorandum which points out that sterilisation of the concentrate will inactivate the virus for AIDS, but not the viruses causing hepatitis. On 23 October 2019 I wrote to the Secretary of State, Rt Hon Matt Hancock, making a FOI request for production of the reply by his predecessor Minister to the letter from Dr Evans dated 8 January 1985 and GRO-
GRO-B
'WITN3854008'. I have not received a reply at the date hereof and on 4 January 2020 I spoke to my MP to expedite this request. She has promised to contact the Secretary of State forthwith.

17. At about this time I also wrote to the National Blood Transfusion Service. I exhibit a response dated 23 January 1985 at **'WITN3854009'** which confirms that since December 1984 they had requested all donors to declare whether

they were homosexual in a desire to ensure that all AIDS risk groups were aware of the risk of transmission of infection through blood products.

18. The initial blood products received by [S] were not heat treated. It is likely that initially he had products produced in Elstree, a town which to this day is associated with pharmaceutical manufacturing (see lecture notes, exhibited at 'WITN3854010'). I say this because Professor Longson said, in a lecture given in February 1985, "Now heat-treated material is starting to be used. Output from Elstree diminished-sensible to reduce non-heated production. Not yet available for Factor IX".

19. Heat treated material was not generally available until about December 1985, when [S] was about [GRO-B] years of age. This is confirmed in a letter dated 4 December 1985 from Dr Evans, which is exhibited at 'WITN3854011'.

20. I do not believe that adequate information was provided to us when it should have been. The doctors failed to give us the full extent of the nature of the risk. As stated above we recognised some sort of risk.

21. I was very concerned about the need for purity in the blood products supplied to [S]. To this end, I recall discussing with the doctors (my wife recalls that I pressed for this and she believes that this resulted in the prescription for [S] being accelerated) the need to secure supplies of recombinant FIX. I was always concerned about the need to ensure that risk of infection was minimised. There was a continual tension between (a) the need for the product to stop the bleeding and (b) the possibility that the product would cause infection. I note that doctors recognised the concerns of my wife and myself in this respect. I refer to paragraph 19 of [S] statement and confirm what he says.

22. I cannot say when recombinant products became available for [S]. However, at some stage [S] was prescribed Benefix, a recombinant FIX product. Please refer to [S] statement, paragraph 23, which details when he was treated with recombinant FIX.

23. On the 2 October 2019, I noted the following on-line description "BeneFIX, Coagulation Factor IX (Recombinant), is a purified protein produced by recombinant DNA technology. The product is formulated as a sterile, non-pyrogenic, lyophilized powder preparation intended to be reconstituted for intravenous injection. It is available in single-use vials containing the labeled amount of Factor IX activity, expressed in International Units (IU). Each vial contains nominally 250, 500, 1000, 2000, or 3000 IU of recombinant coagulation Factor IX. The potency (in IU) is determined using an in vitro one-stage clotting assay against the World Health Organization (WHO) International Standard for Factor IX concentrate." (<https://www.rxlist.com/benefix-drug.htm>).

24. As stated above, on the 3 February 1985 I attended a lecture given at Sparshott House Manchester, the University of Manchester Haemophilia Centre. I exhibit a program at 'WITN3854012' showing that Professor M Longson, Professor of Virology, Manchester Royal Infirmary was a principal speaker. I took notes of his lecture which I exhibit at 'WITN3854010'.

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GRO-B

GRO-B

I draw

attention to the statements that heat-treated material was starting to be used and that it was sensible to reduce non-heated production. Also, with reference to FIX, Professor M Longson noted that "heat-treated material was not yet available and there may be other ways apart from heating for FIX e.g. ultra violet heating". I also draw attention to the statement that at the time of the lecture there were 108 people in the UK that contacted AIDS and 2 or 3 of those people were haemophiliacs. I cannot remember in detail whether anyone else was present at the lecture in addition to those listed on the programme I have produced. Dr Evans was present as a panel member; he is listed as such on the programme - he was always very active in relation to the issues surrounding haemophilia. In addition to Dr Evans and Professor Longson, two other medics were on the panel - Dr Delamore and Dr Wensley.

25. I exhibit at 'WITN3854013' a leaflet produced by the Government in 1985. This confirms that AIDS had occurred in a small number of Haemophiliac

patients. It is hardly surprising that [S] who was about 11 at this date, was worried, even though a letter from Dr Evans dated 4 December 1985 (exhibited at 'WITN3854011') confirmed that he was negative for HTLV (i.e. the AIDS virus). In the letter I draw attention to the fact that "Now that heat treated materials are available." This shows heat-treated FIX was available by December 1985.

26. As a result of prescribed infected blood products [S] was infected with Hep B. My wife and I were aware of this, as is clear from the letter to us from Dr Evans dated 27 November 1984 which is exhibited at 'WITN3854006'. [S] was also infected with Hep C as a result of prescribed infected blood products. However, we were not aware he had been affected with Hep C until he told us in or about late 2018/early 2019. Please refer to [S] witness statement for further details in relation to how he found out about the Hep C infection.

27. I cannot recall if adequate information was provided to us to help us understand and manage Hep B at the time. I believe it was because we found out that [S] was infected with Hep B after he had cleared it.

28. The medical staff did not warn us that hepatitis could have been transmitted. I can say this categorially because we would have been more wary of ourselves and our other son.

Section 3. Other Infections

29. I don't believe [S] contracted any other infection but the more I review the facts the more I am driven to the conclusion that the glandular fever and depression that he suffered may well and probably were in consequence of Hep B and/or Hep C.

30. I don't know if there was any mention of vCJD to [S] [S] did not discuss this with us.

31. Please refer to [S] statement in relation to this section for further information in relation to other infections.

Section 4. Consent

32. I refer back to exhibit 'WITN3854011' (letter dated 4 December 1985), which confirms that [S] tested negative for HTLV-III. I do not recall being told that he was going to be tested for it. As stated above, I attended a lecture in the same year where Professor Longworth was referring to the risk of AIDS. I suspect that I would have asked Dr Evans what was happening at the time, and if he could provide leaflets. I do not believe that I would have ignored them. I must have been concerned about it. I have seen no letter stating that they were going to test [S] for HTLV-III.
33. I believe [S] was tested without being given adequate or full information.
34. I do not know if [S] was tested for the purposes of research. I would hope he was not tested for this purpose without our informed consent.

Section 5. Impact of the Infection

35. The more I reflect the more I believe that the essence of the mental issues and the depression suffered by [S] were attributable to his treatment for Christmas disease and the failure to fully understand and/or to make available adequate products at an earlier stage. Funding is the issue that keeps coming up in this respect. I feel it was a causative relationship. [S] suffered from depression but eventually he got himself off the antidepressants. At a very difficult time in his history the NHS was unable to offer in-patient treatment and so my wife and I arranged for [S] to be admitted into a private hospital in Greater Manchester Hospital and we paid £11,000 for his treatment for depression. This was not refunded to us. Fortunately the treatment helped him enormously at that time.
36. [S] statement explains how the infection had affected him. As parents, my wife and I tried to do our best to protect and help [S] and we may have made the wrong decision by not sharing enough information with him in

his teenage years. We regret that but hindsight is a wonderful teacher. At the time we believed we were acting in his best interests.

37. [S] cleared both Hep B and Hep C naturally.

38. My relationship with [S] in his teenage years was very difficult. I would not let him play football because we feared he would sustain a serious injury requiring additional treatment with additional risk of infection from contaminated blood products. This was a great shame because [S] had shown great ability as a footballer as he demonstrated on holiday in Majorca when he was about [GRO-B]. Nonetheless, the matters described by [S] in his statement show that the infections he contracted from blood products had an adverse impact on his physical and mental health.

39. It was a dilemma; he now has arthritis due to not treating himself enough. But there was always a risk that he may have been infected with AIDS and die as a result. I think [S] now understands our reasoning at that time. We certainly have a very good relationship now. The fear I always had was that [S] would contract HIV from FIX. I find it difficult to find words to express the real tension in my mind between knowing the clotting factor would heal his physical injury whilst at the same time potentially infecting him and killing him. That's a very difficult question to have to juggle with in your mind. This also explains why I did encourage [S] not to treat himself perhaps as often as he should have done. The dilemma was whether to treat for the immediate problem or not to treat for the immediate problem and preserve life, or at least reduce the risk of death. That was a real issue in my mind and the mind of my wife, which we conveyed to [S] whether expressly or inevitably.

40. I feel I should and could have done more but it was the fear of alerting people that [S] had Haemophilia that held me back. Throughout I was worried about [S] identity being known to our neighbours and people around due to the stigma that was associated with haemophilia and HIV/hepatitis. We kept it quiet which is why I feel guilty for not utilizing contacts I had to stir things up earlier. I don't mind so much now because what matters is what [S] thinks. I suspect there is still a stigma attached to hepatitis.

41 [S] health had a significant impact on me [GRO-B]
[GRO-B]
[GRO-B]

There were times it meant I could not work as efficiently as I should.

42. My wife spent a lot of time with [S] looking after him, especially when he was suffering from depression. She provided the main care because at the time [S] and I did not have a good relationship. At one stage I went to stay in hotels and in a residential library in [GRO-B] [S] also stayed for a week or two with some friends when things were very difficult between us. These friends helped bring us together.

43. Jason Evans said recently on Sky news that he has evidence from 1974, the year [S] was born, that there was knowledge of risk of infection from blood products. I have exhibited above evidence from 1976 that there was knowledge of risk of infection. My wife and I were very disturbed and distressed to hear this news. In addition, on 3 January 2020 I read a report in the Daily Mail page 26 "HIV scandal; Why didn't NHS use safer blood product from Scotland". This quotes from a letter released to Jason Evans under the Freedom of Information Act which confirms that there was "very substantial" spare capacity near Edinburgh for the production of FVIII. It appears that government officials rejected the idea of using facilities in Scotland to help the NHS in England and Wales. If this is correct I consider the NHS and the government were in breach of the duty to care properly for patients and their families and this breach has caused considerable harm and loss to [S] and indeed to our family. This material has caused my wife and myself considerable distress. We have not yet informed [S] of this article because he is on holiday. I exhibit a copy of the newspaper article at 'WITN3854014'.

44 [S] education was also adversely affected as a result. As he explains in his statement, his transition to university was through the clearing system, but having secured his place at [GRO-B] he graduated with an excellent degree. I recall one particular occasion when [S] had a serious bleeding episode whilst staying in a hall of residence in [GRO-B] I drove from [GRO-B] to [GRO-B] through the night and took him to [GRO-B] where he was

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admitted [S] had to stop a young doctor injecting him in his thigh muscle. If that had been done a serious bleed would have ensued. My wife and [S] brother [GRO-B] drove down early Sunday morning to join us in [GRO-B] and to support [S]. We all stayed in [GRO-B] for a few days, this was a very worrying time for all of us and [GRO-B] lost schooling also.

45. Some years later, having worked in [GRO-B] [S] graduated with an [GRO-B]. My wife and I were very proud of his ability, perseverance and dedication.

46. I made my file of documents (medical records and documents that I had over the years) available to [S] when he wished to become involved in this Inquiry. My wife and I wondered if we should make it available to him as we were worried it might bring back memories and cause him hurt and upset, but we decided he would gain and would be able to help others. [S] has been involved in the Inquiry with a view to helping others and that is a further source of pride to my wife and myself.

47. My wife and I joined the [GRO-B] when [S] was diagnosed with haemophilia. We received literature which I have retained and [S] refers to some of it in his statement. We made donations towards its work.

48. Our second son [GRO-B] is a very happy and go lucky person. He is [GRO-B] years younger than [S] and they are very close. I always felt it was difficult for [S] because his brother was a very gifted footballer. We had to try and deal with both boys fairly.

49. My wife was more level headed then me. She could deal with [S] in a more unemotional manner. I remember when [S] was diagnosed with haemophilia he was taken into the operation theatre, I broke down but my wife was able to remain calm. My wife home treated [S] because I could not get myself to do it.

Section 6. Treatment/care/support

50. It is my belief that greater emphasis should have been given on the need to convince parents to participate in counselling sessions. As a parent one seeks to do one's best for the welfare of one's child, but confronted with something so out of the ordinary as the issues surrounding infection through blood products in the 1980s, I consider that the Government should have introduced robust and effective counselling services for everyone.

51. I don't recall any robust counselling or psychological support being offered to me at the time. If there had been a robust approach I think it would have helped.

Section 7. Financial Assistance

52. I wish to rely on statement in relation to this section.

53. My wife and I never received any financial assistance from any of the Trust and funds that were set up.

54. As stated above we paid £11,000 towards private treatment for .

Section 8. Other Issues

55. On the 7 July 2000 I attended a reception at the House of Lords hosted by Lord Morris of Manchester and sponsored by the Haemophilia Society. I thought that was part of the campaigning, which it probably was in part, but they utilised it as part of their 50th anniversary. I exhibit the guest list at 'WITN3854015'. I recall meeting Dr Evans there. I remember speaking also to a representative of Bayer Pharmaceuticals, and I have noted "Bayer" at the side of the name Mr Jon Hemphill. It is clear members of Parliament were beginning to ask questions about the blood products.

56. I believe one of the purposes of the House of Lords reception referred to above was to campaign for an Inquiry into infected blood products. It is a matter of regret that successive governments refused to sanction a public

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Inquiry. I am pleased that Mrs May took a different view. Sadly, however, as the years have gone by a lot of written evidence has been lost.

Anonymity, disclosure and redaction

57. I am seeking anonymity and would like my statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry.

58. I do not want 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 *January 7, 2020*