



Witness Name: GRO-B

Statement No.: WITN000655/002

Exhibits: None

Dated: 15 January 2019

INFECTED BLOOD INQUIRY

FINAL WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29th October 2018.

I, GRO-B will say as follows: -

1. Introduction

- 1. My name is GRO-B My date of birth is GRO-B 1960 and my current address is GRO-B London GRO-B I am a legal adviser who qualified as a solicitor in November 1985 but removed myself from the Roll in 2010 and now provide legal and business affairs advice through my company. I intend to speak about my infection with hepatitis C ("HCV") through blood products administered to me as a mild haemophiliac in 1983.

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2. How Infected and history

2. I was diagnosed as having mild haemophilia in 1972 when I was twelve years old, following a dental operation at my local dentist's in Gloucester. The diagnosis was performed at, and I was subsequently under the care of, the Haemophilia Unit at The Churchill Hospital, Headington, Oxford (to which I will refer below as "CHHU"). I did not at any time from 1972 to 1983 experience any difficulties as a result of my mild haemophilia nor did I need to change my lifestyle in any way.

3. In the last week of July 1983 when I was 23 years old, I had all four of my wisdom teeth removed in an operation at The John Radcliffe Hospital Oxford ("the JRH") also in Headington and close to the CHHU. However, although the operation was at the JRH, and I stayed in a ward for about four days after the operation, I was visited regularly by doctors from the CHHU who, before and after the operation, administered factor VIII to me. After the operation I received doses of factor VIII at least twice a day, as I recall. Although there were several doctors, I believe that the doctor who most regularly attended me was Dr.Desani, who was a relative newcomer to the CHHU. After about four days I went home.

4. Before and after the operation I received what was described to me at the time as "British heat-treated factor VIII". I was told that this was a new kind of factor VIII which the CHHU wanted to test on as many haemophiliacs as possible; and that those haemophiliacs who needed less of it (e.g mild haemophiliacs who did not need it regularly) would be the best to take part in the tests because the available products would go further and not all be used up on a small number of patients.

5. I have no recollection about whether I was told why or if this British heat-treated factor VIII would be better than what was ordinarily used; nor whether there was any statement or implication that the ordinarily used factor VIII was dubious or tainted; nor whether the ordinary factor VIII was not British; nor that

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there were any risks of infection with anything else, hepatitis or otherwise. I also have no recollection of having signed any consent forms or the like. My recollection is that it was just a conversation with doctors around the bedside in the ward when I was admitted, and had not been mentioned before then. I was happy to be a "guinea-pig" but I do not think that any one thing in particular was the most important factor. Had I been told that there were fears or evidence that ordinary factor VIII was tainted I am sure I would have remembered it. I have recently asked my mother, who was present when these matters were discussed with the doctors, and she has no recollection of any warnings being given or even an explanation as to why the CHHU wanted to test the heat-treated factor VIII. She simply recalls being pleased, but probably for no other reason than an instinct that British NHS products would be better (but without any implication of being "safer") than anything else.

6. About one week after being discharged from hospital, I had a severe bleed in my mouth when a gap in my gum from where a wisdom tooth had been extracted become infected. This happened at about midnight, and my parents called an ambulance, which took me from Gloucester to Oxford. We arrived at the CHHU about 1.30am. The CHHU always had a doctor on duty, and as it happened, on the night in question there was a severe haemophiliac already at the CHHU when I arrived, receiving attention. The sole doctor on duty at night was Dr.Desani and I imagine that it was unusual to have two patients arrive needing treatment in the middle of the night. Although I was bleeding badly still, Dr.Desani, who appeared to be under severe pressure on the night, understandably attended to the other patient first and then gave me some factor VIII. I was kept in that night at The Churchill Hospital. I cannot recall when I was discharged again but it would have been two or three days later.

7. I cannot be certain that I received British heat-treated factor VIII on this occasion and I do not know whether there was time for Dr.Desani to have gained access to the stock of British heat-treated factor VIII in the CHHU at the time. When I had been given heat-treated factor VIII before and after the wisdom teeth operation, it had all been planned very precisely. I believe it is possible that in the middle of the night, in an apparent emergency, Dr.Desani

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was only able to locate and give me ordinary factor VIII. However, I have recently discussed the events on that night with my mother, who accompanied me to the hospital and was present when I was admitted. Her recollection is that upon arrival I was met by a nurse who was assisting Dr.Desani, and that she had all my notes on a clipboard. My mother recalls that the nurse said to Dr.Desani something along the lines of "This one's a special". That leads me to believe that they were aware of the fact that I had received, and should receive, the British heat-treated factor VIII. Therefore, it is probable that I did indeed receive the heat-treated factor VIII on that occasion.

8. On or about 20 August 1983, about a fortnight after my previous discharge from hospital, I was readmitted for a planned circumcision operation. Again, this was performed at the JRH but I was given factor VIII before and after by the team from the CHHU. This time, I was in a ward at The Churchill Hospital itself. I was in for about a week, and the person from the CHHU who on this occasion most regularly attended to me was a doctor whose name I cannot recall but his surname began with B and he was from Iraq. My memory is that once again I received the British heat-treated factor VIII. Had it been different from that given to me at the time of the wisdom teeth operation a few weeks before, I would have remembered.

9. By 12 September 1983 I was well enough to move to London to start my articles at a firm of solicitors.

10. In about February 1985 I was admitted to my local hospital, Queen GRO-B in Roehampton, with a very high temperature. I was kept in for three days and was so hot that an electric fan was placed by my bed continuously while they tried to bring down my temperature. I was never given what I considered a satisfactory explanation other than on being discharged I was told that I had had a "virus". I recall very clearly that while I was in hospital the newspapers were in the middle of a week of hysteria about the spread of AIDS and every front page of the tabloids at the time was making much of the spread of AIDS through various means. At the time this caused me great anxiety, because of the fear that perhaps my factor VIII had been tainted. For some time

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after that I avoided volunteering the fact that I was a haemophiliac or had had factor VIII, as it was impossible to know how people might react. After I was cleared of HCV in 2003 (see paragraph 22 below) I was not so secretive but that is because haemophilia itself is not a matter of shame or embarrassment and I am lucky enough now to be able to say that I do not have HCV. I am sure that at the time of the incident in 1985, there had never been any mention to me about hepatitis, or any other infection risks.

11. At some stage I started to receive visits at home from a nurse at the CHHU called Mary Fletcher whose role was to monitor those who had had heat-treated factor VIII. She would take blood and ask me questions but I cannot recall the detail of what she asked me. Although I cannot be precise about when these visits started, nor the period over which they took place, I believe that I might have had one visit a year from 1984 to 1990. I do not think that I went to Oxford for these meetings. My memories are of Mary Fletcher visiting me at home especially when I lived in a flat which I had bought with my then partner GRO-B in December 1985, from which we moved in December 1987.

12. In Autumn 1985 GRO-B and I applied for a joint mortgage to buy the flat. We took out a repayment mortgage and I know that it would have been necessary to disclose any medical problems. I would definitely have disclosed my haemophilia, but I am sure that no mention was made of hepatitis, nor was I asked to undertake a medical, which leads me to believe that as of Autumn 1985 I was not aware of the fact that I had hepatitis.

13. Towards the end of July 1987, I needed more factor VIII at CHHU after tearing my thigh muscle badly while playing cricket. I went to my GP about three days after the cricket incident when I realised that the discomfort was not getting better and that the bruising was starting to spread down the whole of my leg. The GP diagnosed the tear, and I was taken by a relative to the CHHU. I did not need an operation but I did need factor VIII and was in the Churchill Hospital for about a week, although off work for another week after that. I cannot recall who administered me the factor VIII on a daily basis, nor can I recall whether I again received British heat-treated factor VIII although I assume this

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was the case because otherwise I would have asked questions. I do not recall being told that all factor VIII being used in the country by then was British heat-treated (this was four years after I had first had it) nor that there were any risks of hepatitis or anything else. I am fairly certain that at this point I had not been informed that I had hepatitis.

14. A few weeks later at the end of August 1987 GRO-B and I applied for an endowment mortgage in connection with the purchase of a house. Our offer was accepted at the end of August and on 1 September 1987 we applied for an endowment mortgage with the Halifax Building Society, supported by a life policy with Standard Life. I am sure I disclosed the hepatitis to the insurance company and mortgagee when applying for the mortgage, and my recollection is that as a result the premium was increased but the mortgage was not refused, nor was I required to undertake a medical examination. I would have been keenly aware of the legal need for the utmost good faith in making disclosures when applying for life insurance. The purchase completed in the first week of December 1987.

15. At some time after the cricket incident in July 1987 I was informed by Mary Fletcher (on a visit to our flat) that I had hepatitis. I am fairly sure that this took place before the application for the mortgage and life policy in September 1987. I can recall (as can GRO-B whose recollections of the events I recently discussed with her) that Mary Fletcher told me while the three of us were sitting in the living room of the flat, probably having visited as a follow-up to the administration of factor VIII in the July.

16. Therefore, with the above dates and events in mind, the date upon which I was informed that I had hepatitis was very likely in August 1987. I have always thought, probably based on what I was told at the time, that I was infected with HCV in 1983 rather than 1987, and I was never given the impression that this was anything other than just an unfortunate side-effect that was known as a possibility at the time (though I have no recollection of being warned in 1983). I believe that it is unlikely that Mary Fletcher informed me that it was a result of

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the factor VIII administered at the end of July 1987, because that would have been too soon after.

17. The way in which I was informed was curious. Mary Fletcher was talking to me as if I knew that I had hepatitis and when I asked her what she was saying, she was surprised that I did not already know. Her reaction was to tell me that hepatitis was a common side-effect of factor VIII, even in the heat-treated form, and that there was nothing to worry about though alcohol was not advisable. It was all dealt with in a rather casual manner as if it was not something of much significance. I did not at that time, nor at any time thereafter, receive any specific advice about HCV or how to treat it (in fact I was not aware at the time that there was any treatment available). I do not recall being told that it would go away or that there was anything that could be done about it, other than monitor it with regular check-ups. However, I do remember being informed that hepatitis could develop into liver cancer. At this stage Mary Fletcher was referring to "hepatitis". At a later visit she said that they were now calling it "non-A/non-B hepatitis", and it was only in about 1989 on a subsequent visit from Mary Fletcher that I was informed that it was now known as hepatitis C, and that was what I had. On reflection I think it odd that I was not informed about the infection more formally, and that it was presented as something of little concern, despite the reference to liver cancer. On reflection I do not know why I was not more curious about the nature of hepatitis when informed about it in 1987. However, I think that was partly because not much was made of it at the time, and partly because I had had a schoolfriend who recovered from hepatitis in 1973 which was considered serious but not life-threatening. As my hepatitis was first described as simply "hepatitis" and later "non-A/non-B" I was not aware that the strain of hepatitis now known as HCV was potentially so lethal.

18. Having recently discussed matters with [GRO-B] our joint recollection is that our main question at the time was whether HCV was transmissible to one's partner. I remember being told by Mary Fletcher that it was not, but on a later visit she said that the most recent research was that there had been evidence of some people having acquired HCV when their partners had it, but that in

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each case the couple had also been drug users sharing needles. We were clearly told that there was no evidence that HCV was sexually transmissible, and I have always assumed that that is indeed correct. [GRO-B] and I never asked more searching questions. Perhaps we should have done so, but I am sure that [GRO-B] and I would not have refrained from asking had we thought there was anything to worry about. Later, when we started a family, my condition was mentioned to doctors but it was never an issue. I am sure we asked for confirmation that there was no danger of children being infected during pregnancy and were told, or at least given the impression, that this was not likely. Had there been a danger, that would have contradicted what we had previously been told. Neither of our children, both of whom are now adults, has HCV, nor does [GRO-B]

19. I do not recall being given any literature about HCV nor being offered any counselling or advice, although had I wanted to discuss matters with anyone I am certain that the CHHU would have provided that assistance.

20. I lived with HCV until 2003. During that time I was very often extremely tired though I cannot honestly say (because it is impossible to know) whether that was a result of HCV or just having a young family and a demanding job. I would also say that I was prone to melancholy at times, but again that might have been due to the other factors in life at the time and I cannot know if this was a consequence of HCV.

21. In the early 1990s I took part in some tests conducted by Mrs Alison Bond at the Department of Psychiatry at Oxford University, who was monitoring the psychological well-being and intellectual capacity of those haemophiliacs with HCV who were registered with the CHHU. She was concerned with how such people were coping with having been infected with HCV as a result of factor VIII. I was never told anything about the conclusions drawn from the study about me.

22. In the mid-1990s, being by now firmly established in London, I stopped being registered with the CHHU and instead registered with the Haemophilia

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Unit at the Royal Free Hampstead ("RFHU"). I was regularly monitored by means of annual check-ups on my blood and interviews. In 2002 I was informed by Barbara Subell at the RFHU, the nurse I used to see on my visits for check-ups, that they wanted to trial a new drug treatment using a combination of riboviren and interferon administered orally and by self-injection, which they hoped would rid the body of HCV, and she asked whether I would take part. I agreed. I undertook the course of treatment for 6 months from October 2002 to March 2003, and in November 2003 received a letter from Dr. Thynn Thynn Yee at the RFHU informing me that I was now clear of HCV – it stated that "your HCV RNA was not detectable. It seems that you have achieved a sustained virological response". I continue to have annual check-ups at the RFHU.

3. Other Infections

23. I have not received any other infections as a result of having been given blood products.

4. Consent and Trials

24. I was never treated without my knowledge or consent although I cannot be sure whether I received British heat-treated factor VIII on the occasion referred to in paragraph 6 above. In respect of the trial mentioned in paragraph 22 above, I was fully informed and provided with informative paperwork – I signed a Patient Information & Consent form on 18 October 2002. I cannot recall being told about any risks when I first had factor VIII in 1983. With hindsight, I do not think that things were explained adequately to me when I was informed that I had HCV in 1987.

25. When I was given factor VIII the first time in 1983, and riboviren/interferon in 2002, I was on each occasion taking part in a trial. This was with my full consent.

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5. Impact

26. Although I have never thought that having HCV has prevented me from doing things in life, I cannot be sure that without it my life would have been the same. I have over the years felt very fatigued but I cannot know whether this was caused or exacerbated by HCV. I do not know whether my family was or has been affected by my status.

27. I was concerned about the possibility that HCV might lead to liver cancer but do not think that I was ever properly aware of (nor was I made aware of) the degree of seriousness about this until, ironically, I was informed that I was clear of the virus, when a GP friend of mine showed great relief at the news, more than I had expected.

6. Treatment/Care/Support

28. I have not faced difficulties or obstacles in obtaining treatment, care and support as a consequence of my being infected with HCV. I was not aware that there was any treatment available until the trial of 2002 referred to above. Until then I just "lived with" the HCV.

29. I do not think that counselling or psychological support has ever been made available to me (the psychological trial in which I took part was not counselling) but I doubt that it would have been necessary in my case unless my HCV status had worsened or my test readings had caused alarm.

7. Financial Assistance

30. At some point in 2004 I registered with the Skipton Fund. I cannot recall if this was a result of being informed by the RFHU or of my noticing press reports about its establishment. I suspect the former, because I have a letter informing me that the Skipton Fund had received my application "from your clinician". I received a payment of £20,000 in September 2004 on signing a

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waiver of my rights to sue. I signed this because it seemed that this was the only way to receive compensation, and it was made clear that this was a one-off ex gratia payment – had I refused it there would not have been anything at all. However, in November 2016 I was informed by the Skipton Fund that I was entitled to additional sums – Stage 1 regular payments. The first payment in December 2016 was a lump sum for a whole year, and since then there have been some monthly payments. I have never needed to seek compensation – the Skipton Fund was proactive in contacting me. The scheme has since been taken over by EIBSS/the NHS Business Services Authority. I continue to receive a monthly sum, currently £333 and I have been informed that I am also entitled to a winter fuel payment this year of £519. I understand that currently the payments are likely to continue to about 2021 unless government policy changes.

31. I have not experienced any difficulties or obstacles in applying for and/or obtaining financial assistance, nor have any preconditions been imposed imposed on the making of an application for, or the grant, of financial assistance.

8. Other Issues/Comments

32. My HCV infection was cleared through the use of my treatment in 2002/3. When I was contacted by the Skipton Fund regarding the additional compensation in 2016 I specifically queried whether I was entitled, knowing that those whose HCV had cleared “naturally” were not entitled to compensation. I was informed that because I had been infected with NHS factor VIII, I was entitled even though I am now free of HCV. I can see the logic, in that despite being cleared of HCV, I did live with it for about twenty years after being infected by NHS blood products. However, I do not think it fair that those infected by NHS blood products whose HCV has cleared naturally should not receive compensation for having suffered with HCV (if there are in fact any people who fall into that category).

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33. I have been extremely lucky in that I did not contract HIV through the factor VIII, and my HCV was cleared by the course of treatment on 2003. For those reasons I have never felt centrally involved in the terrible experiences other haemophiliacs have suffered. But the opening of the enquiry prompted me to make this statement in case it is useful, and because many haemophiliacs were infected through blood products who are now unable to tell their stories.

Statement of Truth

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

Signed GRO-B

Dated *15th January 2019*