Witness Name: GRO-B
Statement No: WITN3126001
Exhibits: NIL
Dated: 2nd October 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 9th January 2020.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1948 and my address is known to the Inquiry. I used to be an industrial chemist before becoming a university academic. I am a father of two daughters, and I have one grandson and two granddaughters.

2. I intend to speak about my infection with hepatitis C ('HCV'). In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my life and my family.

3. In 2017, I had a subdural haematoma which had various effects including short-term memory loss and an inability to recall and vocalise thoughts. It is difficult to explain the full impact of this. I was aware of established long term memories which I could act on and respond to emotionally. However, I could not share them with anyone because of the difficulty in communicating them. Although all of the other symptoms associated with the haematoma resolved themselves very well, some of these memory and communication issues persist and have an impact on my ability to discuss past events. While a memory may still be there, it doesn't mean I can discuss it. I find it difficult to recall and discuss things in nearly as much detail as I could have done previously. This means this statement is far more superficial than I would like it to be.

Section 2. How Infected

4. When I was 9 years old I developed a very major bleed in my right knee. I believe it occurred because I got my leg trapped while crawling around under some machinery, the sort of thing children were once allowed to do. I struggled for quite some time to free myself. I was only 9 and didn't make the connection between this and the severe swelling and pain in my knee that eventually developed. Also, because I didn't have any previous history of bleeding our family GP didn't make the connection either.

5. The swelling and pain became so severe that I was admitted to the General Hospital in Ashton-Under-Lyne, Lancashire (now Tameside General). Their suspicion was that I had tuberculosis of the joint and to confirm this, they decided to carry out a biopsy on the knee. It was then they realised that they were dealing with a major haemorrhage. I was rapidly transferred to Manchester Royal Infirmary ('M.R.I') where I came under the care of Professor Wilkinson and his team in the Clinical Haematology Department. They quickly determined that I had haemophilia A. The time that had passed, coupled with the fact that little or no effective treatment was available in 1958, meant the damage to

my knee joint and thigh muscle was severe. My stay in hospital was a long one and I was absent from school for most of one academic year.

6. I did not have any known family history of haemophilia prior to my diagnosis. However, some years later my mother was identified as a mildly affected carrier. I have two daughters who are carriers. My older daughter is an unaffected carrier and has a son who does not have haemophilia. My younger daughter is an affected carrier. She has a daughter who has a high Factor VIII level but is too young, as yet, to consent to the testing of her carrier status.

7. I was originally diagnosed as moderately severe with a Factor VIII level averaging around 4%. However, as I have got older, my Factor VIII level seems to have risen to be typically above 7% and I am now in the mildly affected group.

8. My life was not severely impacted by my haemophilia except, of course, at times when I had bleeds. These were not frequent and were almost always in response to some trauma. When my Factor VIII was at the lowest level I would have probably three or four bleeds per year on average, almost exclusively in the joints and muscles of my legs. However, one of the issues for a mild or moderate haemophiliac like myself is that we may not often recognise a bleed as quickly or as unambiguously as a severe haemophiliac would. This means that we may not always treat bleeds soon enough or with sufficient treatment product to resolve them quickly.

9. Although my bleeds have been known to last for several weeks, my work and family life could accommodate my reduced mobility. This meant it was possible for me to lead a fairly normal life, bearing in mind that what a haemophiliac might regard as a “normal life” is the life they have when they do not have a bleed. I imagine this is not the same as the normal life of a non-haemophiliac.

10. In more recent years the number of bleeds I have had has become even less frequent. I have only had one bleed since 2011, albeit a rather major one, which was the subdural haematoma in 2017 referred to above. All other treatment received since 2011 has been to cover orthopaedic and dental surgery. I believe this is partly because of this increase in my Factor VIII levels. Another reason for a reduction in the number of bleeds might be that I have become a physically less active and rather older haemophiliac.

11. Since my initial diagnosis of haemophilia in 1958, I have been a patient of the haemophilia team at M.R.I. All of my treatment for haemophilia and other related medical problems have been provided there. I have never received treatment products from any other source. As I tended only to have bleeds in response to trauma of one kind or another, for many years treatment was provided only at the hospital.

12. Like many others of my generation, my earliest treatments consisted of whole blood transfusions or plasma with bed rest, or both, graduating to the use of cryoprecipitate, then blood-derived Factor VIII and eventually to recombinant products. I later self-administered my treatment in response to bleeds for many years. I have never been on prophylaxis. In 2008 I was identified as having a Factor VIII inhibitor and have not self-administered since then, except during periods as an in-patient undergoing surgery.

13. I have had several orthopaedic surgeries, most of which had to be managed haemostatically in the presence of the inhibitor. These surgeries included a total right hip replacement in 1994, a total left hip replacement in 2014, a total right hip revision in 2015 and a bilateral knee replacement in 2017. This necessitated either the use of FEIBA, or, alternatively, treatment with Rituximab prior to surgery to reduce the effect of the inhibitor to allow Factor VIII therapy to be used.

14. As a child I received whole blood and plasma transfusions but that is a long time ago and memory fails me regarding what information was

given to my parents at the time. I have no memory of my parents mentioning the risks of exposure to blood and blood products to me or it being mentioned to them.

15. Like most haemophiliacs, I was eventually identified as being HCV positive. I can't recall receiving any written confirmation of my own HCV infection, but around 1989 I was told that a liver ultrasound scan indicated that there was probably significant liver fibrosis present. By 1990 I was made aware that I had probably been exposed to hepatitis non-A non-B ("NANB") infection. In 1992, the presence of HCV antibodies was confirmed.

16. I was informed of my hepatitis NANB infection by my haemophilia consultant at M.R.I. at that time, Dr C.R.M. Hay (now Professor. Hay), as a consequence of routine blood samples taken at my regular six monthly haemophilia review appointments. I was referred by Dr Hay to the M.R.I. Liver Clinic under the care of Professor Warnes.

17. I continued to attend this clinic for many years during which time regular routine blood tests were carried out, such as liver enzymes tests, plus regular abdominal ultrasound scans. On three occasions I had Dynamic Liver Function tests. I also had a type of scan which involved the intravenous injection of a tracer to try and determine if there was any restriction of blood flow in and around my liver. There was some evidence of reduced flow but nothing to raise undue concern. As part of this investigation I also had a gastric endoscopy.

18. In more recent years the haemophilia team have continued to monitor my liver function and also arrange liver scans. I have never had a liver biopsy. It was suggested by the hepatologists at one point, but I did not consent to it as I regarded the risks of the procedure to be too great.

19. I believe that I was given adequate information to understand and manage the infection. I think that in my case the information I received

was timely and I don't feel that there was any attempt to deliberately withhold information, or for it to be delayed by virtue of a lack of attention.

20. Because of my involvement with the broader haemophilia community over many years, I have received information about current issues, risks and developments from a wide variety of sources. Information has not just come from the medical team responsible for my treatment, but also from sources such as The Haemophilia Society, other haemophiliacs and from my own searches of published medical literature.

21. In my experience, if discussions with your doctors and nurses make it clear to them that there is something you already know, they tend not to see the point of telling you again. I realise that this is not an excuse for failing to inform a patient about the risks of a treatment, but it is an explanation for why it might not always have happened when the medical team regarded you as a well-informed patient.

22. I recall one major event at M.R.I, probably late in the 1980s or early 1990s, in which all their registered haemophilia patients were invited to a public meeting concerned with the risks of HIV infection. There have been other updates since then, either as public meetings or by newsletters or personal correspondence.

23. I can't remember specifically being given any information about the risks of others being infected as a result of my infection, but it was certainly something that I brought up with my consultants because I was already aware of the information available in the public domain. It was not so much a case of me seeking information from them, as me telling them what I already knew.

24. A complicating factor for me, which perhaps differentiates me from other HCV infected haemophiliacs, is that I also have haemochromatosis. Both of these conditions have implications for liver damage and produce symptoms that are the same, even if the principal causes might not be.

My haemochromatosis was diagnosed as a result of blood samples taken to investigate my HCV infection.

25. Prior to my diagnoses of HCV infection and haemochromatosis, I was certainly aware of fatigue that I couldn't account for in terms of my level of activity. It was pointed out to me several times that because these two conditions have such similar consequences I was at a substantially higher risk of severe liver damage. However, largely by virtue of close monitoring and, when necessary, venesections to control my haemochromatosis, it has been possible to minimise this risk.

26. I did not contract HIV, although that does not mean that I might not have been exposed to HIV infected products.

27. In terms of being infected with contaminated blood products, I regard myself as extremely fortunate and very lucky to be alive.

Section 3. Other Infections

28. In February 2009 I received a letter from my treatment centre regarding my possible exposure to nvCJD. I received a further letter in June 2009 which focused on the current understanding of how contamination of blood products might have occurred and the risks that it might pose. I believe my exposure was due to having received treatment from potentially infected batches of Replinate at some time between 1996 and 1998. These batches had included donations from a donor who subsequently died of nvCJD.

Section 4. Consent

29. I have no reason to suspect that anything has been carried out without my consent.

30. I have given consent on various occasions to the haemophilia team and the hepatology and orthopaedic teams for treatments and surgeries. I have been included in genetic studies and have given consent for my data to be included in papers to be submitted to medical journals or conferences. I have also consented to the taking of blood samples to be retained as archived reference samples.

Section 5. Impact

31. One study I consented to being included in was a clinical trial of Interferon with Ribovirin. The course of treatment lasted 12 months from November 1998 to November 1999 and I have remained HCV PCR negative ever since.

32. The trial was to evaluate the effectiveness of the antiviral drug Ribovirin, in combination with alpha interferon, as a treatment for HCV infection. Ribovirin was taken orally and the interferon was self-administered by subcutaneous injection, both over a twelve month period.

33. I was told about the trial by Dr Caroline R. Shiach, one of the haematology consultants at M.R.I., who was in charge of the trial. At the time, a full cohort of volunteers had already consented to be included so, strictly speaking, I had missed my chance of taking part. However, Dr Shiach, obtained permission from the funders of the trial to include me. I assume this would have been the suppliers of Ribovirin but I don't know who they were. She argued that my circumstances of having both HCV infection and haemochromatosis would be of particular interest to the trial.

34. I am glad that for me this trial was successful, but the effects while it was taking place and for some time afterwards were horrendous. I became very anaemic and as a result I was extremely fatigued and unable to function normally. Worse still were the psychological effects. I underwent a complete change of personality. I became very aggressively short

tempered and depressed, and although I did not become violent, it obviously had implications for those around me both domestically and at work. This was one of the worst years of my life.

35. I have already mentioned that my liver condition is monitored routinely by the haemophilia team. This has shown that my liver enzyme results have not given cause for serious concern. Although liver ultrasound scans have from time to time identified liver cysts, these have enlarged, reduced, disappeared or re-appeared on different occasions. I guess it isn't possible to say whether this is due to HCV or haemochromatosis damage, or both.

36. As regards on-going symptoms, fatigue is still an issue. It isn't continual, but when it occurs it is quite debilitating. I can't explain this and don't think this happens in response to greater physical activity. There seems to be an acceptance among the doctors that I have discussed this with that fatigue is an expected outcome of what has been described to me as a "liver that is under some stress".

37. For many of us who were infected, the HIV and HCV infections have had substantial effects on the robustness of our relationships with partners and family members. My marriage underwent difficulties in the 1980s, resulting in divorce in 1990. I have remained single ever since.

38. My wife and I were both aware that HIV and HCV were sexually transmissible. She knew that I was HIV negative but HCV positive. While we could accept this situation and respond to it accordingly, it was stressful for both of us. What else might I have been infected with was also a concern, and whether might that be transmitted to her and our family by other means. I believe the insecurity which this caused served to weaken our relationship, and other unrelated and less major issues that we could have dealt with became disproportionately more significant. The best thing to do in our own interests and those of our daughters was to separate and do so as amicably as possible.

39. After our divorce my wife re-married and she and her husband remained on very friendly terms with me and our daughters. A further dimension to this is the arrangement we reached about the care of children. The eldest was 10 and the youngest 8 at the time, so our plan was that they would be free to live at either of our homes whenever they chose. This meant, however, that for some of the time I was a single parent to two young daughters. I do not want to give the impression that I was unwilling in any way for this to happen, but life did become complicated and stressful at times, especially when I was not in the best of physical or mental health.

40. At the time when HIV exposure first occurred in the haemophilia community, the anxiety associated with it was not confined to those who were eventually shown to have become infected. It was common to us all and was, in itself, to have implications for our relationships with those we worked and socialised with, and of course for our family life.

41. I had never kept my haemophilia a secret from friends or work colleagues, so it was widely known that I might be infected. Unlike many others I did not suffer any overt abuse or aggression, but I was aware that there were those who distanced themselves from me. I eventually found out that I was not infected with HIV, but we all experienced that fear of not knowing whether we were or not. I still don't know whether I was ever exposed to HIV. I have asked but never been able to get a conclusive answer.

42. My infection with HCV has also impacted upon my career. I am an industrial chemist and for the last 20 years of my working life I was a university academic. I progressed steadily up the career ladder to Principal Lecturer with teaching, research, consultancy and administrative responsibilities. It eventually became clear that my health was getting in the way of being able to function effectively. This was particularly so from late 2000. Extreme fatigue and pain were among the

main problems. I loved my work and I was only 56 when I had to retire. I would have continued to work until 65 and beyond if I could have, but that was not to be.

43. The implications on my quality of life are significant. Not only am I disappointed about the loss of what I wanted to continue doing in the latter part of my life, there are also financial consequences. Had I been able to continue in employment, I could have expected significant increases in both my salary and my earnings from consultancy work over the 9 years that I lost, between the ages of 56 and 65. This would also have provided me with a larger private pension than the one I have now.

44. I realise my circumstances will seem like a sob story to some. There are those affected and infected who are much worse off than I am, and my past experience enables me to recognise that only too well. While those in greatest need, whatever that need might be, should always be the priority, there were consequences for all of us irrespective of our starting points and our eventual circumstances. This should not be disregarded.

Section 6. Treatment/Care/Support

45. I haven't faced any major difficulties or obstacles in obtaining or accessing treatment, care and support in consequence of being infected with HCV. There were not any treatments which I considered ought to have been made available to me which weren't. I was always placed at the end of surgical operating lists because I was considered an infection risk to other patients, but that was only an inconvenience and nothing more.

46. My NHS dental practice is aware of my haemophilia and my past HCV status. We agreed some time ago that they will carry out all my routine dental check-ups and do any minor non-invasive treatments that might be needed. For anything else, I would refer myself to my haemophilia team at M.R.I. with a view to it being carried out there.

47. My period on the Ribovirin/Interferon trial was a time when I needed some counselling support for the aggression and depression that I was experiencing. It is true to say that I didn't ask for any support and that was foolish of me, but I did describe my problems to the doctor supervising the trial. While she was scrupulous in monitoring my progress and responding to the problems I was having with anaemia, I think it was remiss of her to have underestimated the psychological impact. I believe that counselling should have been offered to me at that time, but it wasn't.

Section 7. Financial Assistance

48. In 2004 I received the first stage ex gratia Payment via the Skipton Fund. I was not eligible for the second stage payment.

49. In 2013 I applied to the Caxton Foundation for a discretionary grant to help with the purchase of a mobility scooter. An award of £1,110 was made in September 2013

50. Since 2016, I have received the stage 1 regular payments and winter fuel payments. These were first provided via the Skipton Fund and then, from November 2017, by the England Blood Infected Support Scheme (EIBSS).

Section 8. Other Issues

GRO-B *The Manor House Group*

51. Since the early 1960s I have been a member of the Haemophilia Society. I have also, at various points, been GRO-B and GRO-B of the GRO-B of the Society, and a GRO-B of the national Haemophilia Society from 1995 to 2000. I have also been a GRO-B of

the MacFarlane Trust. I intend to set out GRO-B with these groups in a separate written statement.

52. I was aware of my own good fortune because I had avoided being infected with HIV and I felt the need to be whatever help I could. I also had a sense of guilt. The fact that I, an adult who had already been able to have a full and rewarding life up to that point, was spared, when children died after only minimal exposure to infected treatment was profoundly unjust and very difficult to come to terms with.

53. I believed that The Haemophilia Society should be the single vehicle for furthering the campaign for action for both HIV and HCV, but I felt that it wasn't going to be able to do that with the enthusiasm I thought it should. This drove me GRO-B Manor House Group, a group which initially intended to focus on a campaign to get the needs of haemophiliacs with HCV properly addressed. The group's principal aim was to raise the profile within the haemophilia community of those people who had been infected with HCV alone.

54. By virtue of informal contacts that existed between individuals in the various regional groups of The Haemophilia Society, and between those who knew each other through being patients at the same hospital haemophilia centre, there developed an awareness that there were some commonly held beliefs and something of a shared dissatisfaction. There was a feeling at the time that The Haemophilia Society had become more responsive to the Birchgrove Group, whose focus was largely on HIV infection among the haemophilia community, and those with HCV did not feel adequately prioritised.

55. Initially there were about 20 or so individuals who were exclusively from the GRO-B regions of England. The first meeting was held at the home of one of the GRO-B members of The Haemophilia Society and the initial intention was to form a new sub-group within the compass of the Haemophilia Society. The group felt that The Haemophilia Society was focusing on HIV infection and HIV and HCV

co-infection, to the exclusion of members infected only with HCV. Of course, deaths and hardship were occurring in both groups, and haemophiliacs infected solely with HCV were the largest proportion of the overall haemophilia population.

56. GRO-B that first meeting of The Manor House Group and GRO-B GRO-B There was a lot of frustration and anger, and while The Manor House Group functioned as a necessary outlet for it, in my opinion it became a less effective group than it might otherwise have been. I felt that it should focus on key objectives rather than respond angrily on all fronts. I eventually GRO-B ceased to have any involvement because GRO-B acceptable to the members.

57. I can't remember the exact dates in which GRO-B the Manor House Group and I no longer GRO-B refresh my memory. GRO-B GRO-B

58. The group ultimately became frustrated with the responses it got from The Haemophilia Society and divorced itself from it and established itself as an independent charity. As an outside observer, it seemed to me that things did become more focused later.

Other Matters

59. I have heard an anecdotal comment about blood product manufacture from my cousin's husband, who was a GRO-B GRO-B. He knew that I had haemophilia and that I had received BPL Factor VIII. He told me that at one point Glaxo had considered trying to acquire Bio Products Laboratory when it was still called Blood Products Laboratory ('BPL'). BPL changed its name around 1990, so I assume this took place in the mid to late 1980s. Glaxo went as far as carrying out an on-site evaluation of BPL operations at Elstree. Apparently the internal report was scathing

in its condemnation of the equipment, procedures, management and governance of BPL's plasma processing and Glaxo did not pursue it any further.

60. I think we should not lose sight of the difference between being exposed to infection and actually becoming infected. If some individuals were exposed to HIV but did not seroconvert, then the real measure of the problem should be the number of people who were exposed. To regard the number of people who were infected with HIV as being the measure of the size of the problem is misleading and potentially unfair. I don't know if this can be investigated retrospectively because I assume information regarding which batches of products patients received is no longer available, if it ever was. If that information was not collected then I believe that alone is negligent.

61. Since we know the number who were infected with HIV from contaminated blood, could the number who might have been exposed be inferred by analogy with what occurred in other groups affected by HIV?

62. Going forward, we surely must have in our minds at all times that the issue is not just one with a history that we are now trying to put to bed. It is ongoing, it is as much about now and the future as it about the past.

63. If anyone saw it coming and remained silent, they deserve our censure and I really do wish that there will be no nasty surprises yet to come. I hope we don't end up discovering any more dishonesty and unethical behaviour than some of us already suspect or know to have been the case.

64. In the early days when the first infections were occurring, many of us were taken completely unawares by AIDS. We thought that if it existed at all, it couldn't possibly be anything to do with being a haemophiliac, but we were wrong and can be again. Do we have greater awareness of

potential future infections than we had then? Can we safeguard the future better than we did in the past? I hope so but I am sceptical. We must get procedures in place that provide a substantially more secure system for blood and blood products – not just better than we had then, but better than we have now.

Statement of Truth

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

Signed GRO-B

Dated 02 Oct 2020