Witness Name: **GRO-B**
Statement No.: WITN1387015
Exhibits: **None**
Dated: 31 March 2021

INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT
OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 February 2021.

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

Section 1: Your Role and the Structure of the Haemophilia Society

1. The Inquiry is aware that you attended Haemophilia Society Trustee meetings. Please confirm the dates and capacity in which you attended these meetings. [You may be assisted by HSOC0019926_003, MACF0000016_105, HSOC0010529, HSOC0010523].

1. I was a trustee of the Society, I think from 2006 to 2007 (though I am not completely sure of the dates) and I attended board meetings in that capacity.

2. Please detail your relationship with the Haemophilia Society, including details of any work undertaken for or positions held at the Society (if any). If these changed over time, please explain when and why.

2. I was a simple trustee of the Society for a short amount of time; I don't recall having any designated positions or responsibilities and I did not sit on any committees or working parties.

3. I had become more involved with the Society through concern that little was being done for and on behalf of haemophiliacs co-infected with HIV and HCV.

3. What was your understanding of the objectives and functions of the Society during the period in which you were involved? If these changed over time, please detail when and why.

4. The Society's formal objectives are set out in its constitutional documents and I understood them to include the representation of the haemophilia community as well as advancing the understanding of bleeding disorders and the development of new treatment options. I don't believe that these objects have changed.

5. How the Society went about meeting its objectives did change over time. I became involved with the Society out of concern that very little was being done to represent and advocate for haemophiliacs who had been infected through contaminated blood products.

6. I and others held the view that the Society wanted to distance itself from those of us who had been infected and to focus on the younger generation of haemophiliacs who had only ever received comparatively safe treatments. This view was given credence by the fact that the Society was so reluctant to mention HIV that it gave AIDS advocacy funding which it had received from central government to the Birchgrove Group in order that the Birchgrove Group could carry out this function.

7. The Society's approach in this regard did change somewhat over time with the appointment of trustees who could speak to being co-infected (such as myself) and with the appointment of a HIV/HCV Co-ordinator.

4. Were you a member of any of the Society committees or advisory bodies? If so, please provide dates of involvement and describe the purpose, functions and responsibilities of each committee or advisory body (if any).

8. As already noted, to the best of my recollection, I did not sit on any committees or advisory groups whilst I was a trustee of the Society.

5. Please explain what (based on any involvement you had with the Society at any relevant time) your views of the Society were, the reasons for those views, and when you came to those views, in relation to the following specific issues:

a. Their stance regarding Factor VIII usage;

b. How the Society responded to the AIDS crisis at the time;

c. The support offered to those who were HIV positive by the Society in years after the immediate crisis;

d. The provision of information about HIV and AIDS in the literature from the Society;

e. The interrelationship between Birchgrove and the Society.

9. I can largely only answer these questions as a haemophiliac who was co-infected through contaminated concentrates rather than as a result of being a trustee of the Society.

10. I felt that at best, the Society had done too little too late when it came to advocating on behalf of haemophiliacs for safe therapies, at worst, I think it could be argued that they were complicit in the infection of thousands of haemophiliacs.

11. The Inquiry has seen already that the Society was beholden to the UKHCDO which meant that the same group of doctors who were pushing concentrates were also the medical advisors to the Society. In these circumstances, it comes as little surprise that the Society's advice to its members was always in tune with the guidance coming from the UKHCDO. There was no challenge offered by the Society to the UKHCDO's way of doing things and there was an acceptance of the concept that hepatitis was the price to be paid for clotting therapies. This acceptance was naïve because even if one accepts that hepatitis was perceived as harmless (which I do not) there was no consideration given to the fact that eventually, a new blood-borne pathogen would emerge and that haemophiliacs would inevitably be infected with it.

12. With the advent of HIV, this new threat should have sparked some form of challenge from the Society but instead, the Society doubled down on its relationship with UKHCDO and parroted its advice about continuing to take whatever we were prescribed by our haemophilia centres. It is because of the Society's stance on this

point that I say it could be argued to be complicit; many haemophiliacs had doubts about their treatment eased because of the guidance published by the Society.

13. Following the period of HIV infections, the Society tried to turn a page; it did this by simply ignoring the entire issue of infections and placing all focus on the younger generation of haemophiliacs, many of whom had managed to escape infection. This left me felling alone and scared after I received my diagnosis; there was no support, information or advocacy from the Society – I, and many like me, were cut loose. As to the specific question asked of whether there was any literature published by the Society covering HIV and AIDS, if there was, I never saw it.

14. It was the Society's stance (and ineptitude when it came to advocacy for those infected) that gave birth to the campaign groups which have fought for decades now for justice. If the Society had been doing its job properly, there would never have been any need for these groups to be formed.

15. In 1998, I joined the Birchgrove Group which was started by a small group of infected haemophiliacs. Birchgrove (probably like other campaign groups) wasn't simply a campaigning organisation, it offered support and advice to infected haemophiliacs. By this, I mean that Birchgrove wasn't just trying to fulfil the advocacy gap left by the Society's inaction – it was doing everything that the Society ought to have been doing for its members.

16. Birchgrove's relationship with the Society was uneasy and that was in large part because the Society was shying away from the entire infected community. Despite being uneasy, there was a relationship and as I have already mentioned, the Birchgrove Group received funding from the Society, I believe it was also permitted to use the Society's charity number.

17. The money received from the Society paid for things like the Birchgrove Newsletter which was written by infected and affected members of the community and distributed in hard copy, by post. The Newsletter focussed on giving information and advice on infections and the consequences of them, it also advised on how to interact with the MFT. From memory, the Society gave the Birchgrove Group £10,000 per year which would pay for four issues of the Newsletter.

18. My belief is that the Society paid for the Newsletter because it featured articles and information which it didn't want to place in its own publications. My understanding was

that any mention of HIV in a Society publication would likely be disapproved of by the pharmaceuticals who the Society relied upon for sponsorship and funding; I think I also heard the view expressed that the mention of infections by the Society was avoided because it might upset newly diagnosed haemophiliacs.

Section 2: Campaigning

6. Please provide details of any campaigning efforts which were organised by or were performed in conjunction with the Society. In your answer, please include a description and the objectives of your campaigning work with Birchgrove Group.

19. Birchgrove's campaigning work focussed on bringing about a public inquiry and obtaining proper compensation. I can only remember one event which was jointly attended by the Birchgrove Group and the Society and that was when we presented a petition to Downing Street and laid flowers at the door of Number 10. I cannot recall any joint campaigning activities.

7. Please outline the relationship between the Haemophilia Society and the Birchgrove Group. Please set out any differences in approach and/or actions taken by the two groups in relation to campaigns.

20. The Birchgrove Group and the Society were never happy bedfellows. To Birchgrove, the Society wanted to whitewash over the infection of haemophiliacs and their role in it; I believe that there was a feeling at the Society that infected haemophiliacs ought to move on with their lives, but we couldn't because we were living with the day-to-day effects of HIV and HCV coinfection.

21. I think that Birchgrove tried to do all of the things for infected and affected haemophiliacs that the Society ought to have been doing and the main vehicle for this was the Newsletter. The Newsletter included stories from infected and affected people with the intention that those reading would see that they weren't alone in the struggles they were facing. Later, the Newsletter included information and articles which we sourced from the US on the latest HIV treatments so that people could understand the options open and have some understanding of the drugs they were being prescribed. This is something that the Society would never have done at the time although in subsequent years they did publish a few information sheets on HIV meds.

22. In terms of campaigning, the fundamental difference was that Birchgrove was not afraid to shock or rock the boat. As an example, at the time when recombinant was being introduced, a number of members went on treatment strikes until recombinant was provided for all haemophiliacs. The Society's approach was to write the odd letter and perhaps have a conversation with a politician.

23. Additionally, when new anti-viral treatments were introduced, Birchgrove members kept treatment diaries where they catalogued their experiences and the side effects they suffered. The best example of this with PEGylated Interferon where patients were warned of mild flu like side effects and the reality, almost universally, was significantly worse.

24. The lack of any close relationship between Birchgrove and the Society was typified by the Society's refusal to have anything to do with (or provide any funding for) the Birchgrove Woodland Grove – even the MFT made a contribution to this.

8. What positions and assurances were made by the Government to any campaigns you were involved with in relation to compensation for haemophiliacs infected with HIV and/or Hepatitis C during the relevant period?

25. I do not recall ever receiving any direct assurances from government about compensation for HIV or HCV infections whilst I was a trustee of the Society or as part of the Birchgrove Group.

Section 3: Relationship between Haemophilia Society and Trusts & Schemes

9. Please set out the extent to which, to your knowledge, the Macfarlane Trust and the Haemophilia Society worked together on any projects or issues relevant to the Inquiry's Terms of Reference.

26. Having been a trustee of both the MFT and the Society, a beneficiary of the MFT and a member of the Society, I cannot recall any significant project where the two organisations collaborated save for the events which are referred to below.

10. The Macfarlane Trust organised projects and events which were supported by the Haemophilia Society. What form did this support take? Did the Haemophilia Society provide any financial support for such events? Please provide as

many details as you can about this aspect of the relationship between the two organisations. [You may be assisted by MACF0000004_035, page 2 and MACF0000012_087, page 4].

27. I do not recall any significant collaboration between the Society and the MFT though plainly, from the documents to which I am referred, there was a small amount which looks to have centred on weekends away. I do not know whether the Society provided any financial support for these weekends but I believe the support probably refers to sending someone from the Society to give a talk during the weekends.

28. Again, with the Chief executive's report at MACF0000012_087, it seems that there was a collaboration on a mentoring project but I cannot remember it unfortunately.

11. Please describe the relationship between the Partnership Group and the Haemophilia Society. Was there any collaboration on activities between the Group and Haemophilia Society? Did the Haemophilia Society provide funding for the Partnership Group? [You may be assisted by MACF0000088_027, page 2].

29. I do not recall any real relationship between the MFT's Partnership Group and the Society save that members of the Partnership were often members of the Society too and of course, user trustees like myself sat on the MFT board and at Partnership Group meetings as well as being members of the Society.

30. There was occasional attendance at PG meetings by Society representatives such as GRO-D but I'm not aware of the Society having funded the Partnership Group nor do I recall any formal collaboration on any issue.

12. In the Partnership Group meeting, held on 16 November 1999, members stated "that although some Macfarlane Trustees were fully supportive of the needs of registrants as they related to co- infection and hepatitis C, there were others who, because they were Trustees of the Haemophilia Society, demonstrated by their support of The Society's Campaign for those who were 'mono-infected', that they were not supporting Trust registrants" [MACF0000088_027, page 2]. Please can you elaborate on these concerns. Why support for the Society's campaign for those who were mono-infected potentially regarded as a "conflict of interest"?

31. I don't have any recollection of the discussion on conflict of interest but rivalries between different factions of the infected community were forged by the piecemeal fashion in which support had come about over the years. At the time this discussion took place, there would have been understandable resentment from the mono-infected that they were receiving no support whilst there was probably a degree of caution from the coinfected community that any payments for mono-infection would reduce the support that did exist for coinfection.

32. Given the passage of time, I think that this is the best answer I can give.

Statement of Truth

I believe that the content of this statement is true.

Signed:… **GRO-B** …………………..

GRO-B

Dated this 31st day of March 2021