Witness Name: Norma Guy
Statement No.: W52510001
Exhibits: None
Dated: 27th April 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF NORMA GUY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 December 2020.

I, Norma Guy, will say as follows: -

Section 1: Introduction

- **Please set out your name, address, date of birth and professional qualifications.**

1. My name is Norma Guy. I live at GRO-C Lancashire GRO-C I was born on GRO-C 1939. At the time of writing this statement, I am 81 years old. I do not have any professional qualifications.

- **Please set out your employment history, including the positions you have held, the dates that you held these positions, the organisations in which you held these positions and your role and responsibilities in these positions. If it is more efficient, a CV could be annexed at this point.**

2. When I was 15 I trained as a telephonist at a GP practice. I then went to the education office as a telephonist, where I worked for 15 years. After that, I worked in a nursing home as a carer. I then went to North British Housing where I would man the emergency call switchboard. It was a job that required an immense amount of responsibility, having to deal with crisis situations. I retired in 2003, when I was 63.

- **Please set out your membership, past or present, of any committees, groups, associations, societies or working parties relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.**

3. I was the Chairman of the North West Group of the Haemophilia Society for 25 years. I started at the North West Group in the early 1980s. I became interested because a friend of the family has haemophilia. He was also on the North West Group committee.

4. I was on the Executive Committee of the Haemophilia Society between 1991 and 1996. Reverend Alan Tanner and David Watters invited me onto this committee. Andy Cowe and Nicholas Lawson proposed me and seconded me and I was then voted in.

5. I joined the Macfarlane Trust Committee ("MFT Committee") in 1993.

6. I was also a member of the Manor House Group.

Section 2: Previous Evidence

- **Please confirm whether you have provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. If you have, please provide details of your involvement and copies of any statements that you made.**

7. I have not given any evidence to any inquiries, investigations or litigation in relation to the above.

Section 3: Your Role and the Structure of the Haemophilia Society

- **When you joined the Haemophilia Society, what were the objectives and functions of the Society? If these changed over time, please detail when and why.**

8. During my tenure on the Executive Committee, I considered the main purpose of the Society to be to apply pressure. It would write to consultant haematologists in an attempt to stop them using contaminated blood products. The pressure was applied mostly in writing. David Watters would also travel the country to persuade doctors to this end. The Society also campaigned for compensation for those infected through blood products, which I speak about in paragraphs **87-102** of this witness statement.

- **The Inquiry is aware that you were a Committee Member of the Haemophilia Society between 1991 and 1996, and prior to that, a Committee Member of the North West Group of the Haemophilia Society in the 1980s. Please confirm the dates of your tenure at the Haemophilia Society and explain what your role and responsibilities were in relation to your role and how your role and responsibilities changed over time.**

9. The approximate dates of my tenure are detailed in paragraph 4 above. As a member of the Executive Committee, I attended monthly meetings in London when I could, where we discussed an agenda that was circulated in advance.

- **Please list all the different Haemophilia Society sub-committees, task groups and advisory bodies that you were involved in and describe the purpose, functions and responsibilities of each committee, task group and advisory body. Please include a description of the Resources Subcommittee, Services Committee, the Hepatitis Task Group, the HIV Task Group and Committee B and the extent and period of your involvement.**

10. I do not recall being on the abovementioned committees, but I have a distant memory of attending hepatitis task group meetings. These started in the mid 1990s. I cannot remember who was on the committee or what it did, although I do remember that Simon Taylor ran it. I was a member of the Manor House group. It is more than likely that I was at meetings of the above committees to represent the views of the Manor House Group, which sought to put pressure on the Society to keep hepatitis C at the front of its mind.

3.1 The Hepatitis Task Group

- **The Inquiry is aware that you were involved in the work of the Hepatitis Task Group** [HSOC0003743; HSOC0003794]**. To the extent that you have not already answered, please explain what the aims of the Hepatitis Task Group were.**

    a. **When was it established? What prompted the Society to set up this task group?**

    b. **What resources (if any) did the Group rely on for medical or scientific opinions?**

    c. **Who were the members of the Hepatitis Task Group and how were they selected?**

    d. **Please explain what the Hepatitis Task Group did during the course of your tenure at the Society.**

- **What role did the Hepatitis Task Group play in the campaign for compensation for people infected with HCV** [HSOC0023353]**?**

- **What was the Hepatitis Campaign Group? What (if any) was the relationship between the Hepatitis Task Group and the Hepatitis Campaign Group** [HSOC0026495]**?**

- **Please describe the relationship between the Hepatitis Task Group and the Manor House Group** [HSOC0023353; HSOC0015306]**. What was the purpose and function of the Manor House Group?**

11. The Manor House Group was a separate group that put pressure on the Haemophilia Society and the press in order to: bring attention to hepatitis C, keep the issue in its consciousness and in the public eye. We wanted the Manor House Group to have a say in the Haemophilia Society's policy decisions, but they were resistant. I got the sense that, initially, the Haemophilia Society's Executive Committee saw the creation of the Manor House group as unnecessary and felt it was overriding the Haemophilia

Society's efforts. The relationship between the two entities improved over time and they became more transparent and cooperative with each other.

12. I think my involvement in the hepatitis task group was by virtue of my membership of the Manor House Group and the Executive Committee. The hepatitis task group would write letters to ask for compensation on behalf of all infected members. I do not recall being a member of any hepatitis groups separate to that involvement, and I do not remember much, if anything about these meetings.

3.2 HIV Task Group

- **The Inquiry is aware you were involved in the work of the HIV Task Group [HSOC0023418]. To the extent that you have not already answered, please explain what the aims of the HIV Task Group were.**

13. I was not particularly involved in the work of this task group. I think I went to some of these meetings because they were part of the Executive Committee meetings.

- **When was it established? What prompted the Society to set up this task group?**

14. I do not know.

- **What resources (if any) did the Group rely on for medical or scientific opinions?**

15. I do not know.

- **Who were the members of the HIV Task Group and how were they selected?**

16. The people on these tasks groups were members of the Executive Committee. I think they had to be. They would volunteer to be on the sub-committees and task groups. Some Executive Committee members sat on so many committees, whilst others, like Simon and Andy, had jobs so could not attend all of the meetings.

- **Please explain what the HIV Task Group did during the course of your tenure at the Society.**

17. I do not remember anything specific, only that it existed.

- **Please outline the relationship between the HIV Task Group and the Birchgrove Group. Please set out any differences in approach and/or actions taken by the two groups.** [HSOC0023418; HSOC0023357; HSOC0029690_052].

18. I was never a member of the Birchgrove Group. Their focus was HIV. A lot of them came from Newcastle, or near Newcastle. They were rebellious and the Haemophilia Society were not very happy about them, that is all I know about them. I did not get involved and did not want to have much to do with them. There was a bit of hostility between the group, which I knew of from Simon telling me. Unlike the regional groups of the Haemophilia Society, which were self-funded, the Birchgrove Group wanted the Haemophilia Society to hand them money all the time. They seemed to think their cause was the more important and they were entitled. That is one of the reasons I objected to the group.

3.3 The Medical Advisory Panel

- **To the best of your knowledge, please describe the purpose, function and responsibilities of the Medical Advisory Panel. If this changed over time, please set out this information according to applicable time frames.**

19. I cannot remember much. I remember that the Society sought advice from the following doctors, although I did not know them as the Medical Advisory Panel.

    a. Dr. Peter Jones;
    b. Professor Arthur Bloom;
    c. Dr. Christine Lee;
    d. Dr. Elizabeth Mayne;
    e. Professor Charles Hay;
    f. Dr. Geoffrey Savidge; and
    g. Dr. Paula Bolton-Maggs.

20. I also remember that Sister Shaw and Dr Evans advised the North West Group of the Haemophilia Society. I think Dr Evans advised the National Society too.

- **To what extent (if any) were the opinions of the members of the Society's Executive Committee informed by the Medical Advisory Panel? What other resources (if any) did committee-members rely on for opinions on the safety of blood products and/or the risks of infection from hepatitis and HIV?**

21. The panel of medical advisors I have described above had an awful lot of influence on the Committee. Reverend Tanner always seemed to report on what had been said by the Medical Advisory Panel in the Executive Committee meetings. I do not think the function of the panel changed during my tenure.

- **How did the Haemophilia Society select members of the Medical Advisory Panel? What criteria were used, if any? How did membership change over time? [You may be assisted by** PRSE0000956 **which sets out the membership in the 1980s.]**

22. I do not know whether there was a criterion to select members of the Medical Advisory Panel and I cannot recall how the membership of the panel changed over time.

- **In a brief on the Medical Advisory Panel, dated 7 November 1991** [HSOC0010470] **Mr Watters stated that the Medical Advisory Panel consisted "of "favoured" Reference Directors plus, more recently, other Centre Directors". Were you aware that some Reference Directors were "favoured"? If so, what did you understand by it? Who were the "favoured" Directors that were referred to here?**

23. The phrase "favoured Reference Centre Directors" resonates with me. Whilst I was on the Executive Committee, I felt some Centre Directors held more sway over the Committee than others—especially those from or near London. From this distance, I cannot recall who exactly was more favoured. I once mentioned to Reverend Tanner about some Centre Directors being favoured over others. Of course, he disagreed with me. But I also spoke to David Watters about it, who was of the same opinion as me.

24. Dr Geoff Savidge was always favoured by the National Society. He was a sweet talker, who could sell snow to Eskimos. Professor Arthur Bloom was also particularly favoured. Reverend Tanner especially regarded Professor Bloom very highly. He used to bring his name up a lot at Executive Committee meetings. It gave me the impression that Reverend Tanner considered Professor Bloom to be the font of all knowledge.

This was until Professor Bloom's death in 1992. The Executive Committee also highly regarded Dr Mark Winter and his advice.

- **Please clarify:**

    a. **How was advice sought from the Medical Advisory Panel?**

    b. **Who decided when advice would be sought?**

    c. **Was advice sought from all members of the Medical Advisory Panel or only a selection of them? If a selection, how was that selection determined?**

    d. **How were matters discussed by members of the Medical Advisory Panel?**

    e. **Did some members of the Medical Advisory Panel have more influence than other members, and if so, who carried more influence than others?**

    f. **Were matters discussed at times other than the in-person meetings of the Panel?**

    g. **How was advice communicated from the Medical Advisory Panel to the Society?**

    h. **How was the Panel's advice recorded once it was received by the Society?**

    i. **In relation to what issues relevant to the Inquiry's Terms of Reference, did the Society seek the advice of the Medical Advisory Panel and what was the advice provided by the Panel on those issues?**

25. The Medical Advisory Panel were always consulted in writing. Generally, when we sought advice we would go to about three, maybe four members of the panel to get a consensus; we did not tend to consult the whole panel. I do not know who made the decision to consult the Medical Advisory Panel or which doctors would be consulted but any request had to go through the chairman. The advice was then delivered by the Chairman at an Executive Committee meeting. This advice was recorded on the

minutes, which was David Watters' job. Sometimes members of the Medical Advisory Panel would be invited to talk at the Society's national conferences held in London but as far as I can recall they never addressed the committee directly. I am unable to recall any specific advice we sought because it was a very long time ago.

26. We did not necessarily distribute all the advice that was given to us, although I cannot say for sure. The matters that were discussed within the Executive Committee meeting got would not go out to the National Society. All of the Executive Committee documents would be marked "embargoed" and we were not to discuss it outside the Executive Committee meetings.

- **As far you can recall, please describe:**

    a. **The extent to which the Haemophilia Society relied on its own judgement when deciding whether or not to formulate policy on the basis of the Medical Advisory Panel's advice;**

27. When formulating policy, we would have a vote on whether we agreed with the advice or not.

    b. **All examples, relevant to the Inquiry's Terms of Reference, of when the Society did not follow the Medical Advisory Panel's advice;**

28. I cannot remember any actual instances of that happening.

    c. **All examples, relevant to the Inquiry's Terms of Reference, of when other members of the Medical Advisory Panel disagreed with the advice of the Chair of the Panel;**

29. I do remember occasions when Reverend Tanner disagreed with the advice given. I cannot remember the specific occasions, subject matters or clinicians he disagreed with, but it certainly happened more than once. I never saw this disagreement recorded on any of the Executive Committee Minutes.

    d. **All examples, relevant to the Inquiry's Terms of Reference, of when the Haemophilia Society did not follow the advice of the Chair of the Medical Advisory Panel.**

30. Most of the time the Executive Committee followed the advice it was given. There might be one or two members who would make an argument about it, but we tended to follow the advice: it was subject to a vote by the Committee members and the majority tended to agree with the advice provided by the Medical Advisory Panel.

- **In 1991, the Haemophilia Society conducted a review into the workings of the Medical Advisory Panel. Could you please provide examples of circumstances, relevant to the Inquiry's Terms of Reference, of how the below concerns arose [you may be assisted by considering** HSOC0010277**]:**

  a. **The representatives of the Society and the members of the Medical Advisory Panel felt disappointed with the substantive outcomes of their meetings;**

31. I think Andy Cowe objected a few times to a more formal arrangement with the Medical Advisory Panel. He was of the view that it was unnecessary and ineffective to have a large panel because it was harder for them to come to decisions and for the Society to know the way forward.

32. David Watters was always objecting to the Medical Advisory Panel's Advice. David was very knowledgeable and, when he had started at the Haemophilia Society, researched a lot into haemophilia. Reverend Tanner and all the staff at the Haemophilia Society relied heavily on David Watters for his opinion, both on executive decision making and matters that were more of a medical nature. I got the feeling that David, on occasion, felt that the research he had done and expertise he had gained were overridden by the Medical Advisory Panel. But as he was just the General Secretary, he did not necessarily have the right to object in this way. I am unable to recall any specific examples.

  b. **The Society representatives felt that it was sometimes difficult for the Medical Advisory Panel to, "*take off their Centre Directors' hats and give independent advice*";**

33. I cannot recall the specifics, but I do know that it did happen.

c. **The Society's representatives felt that the meetings of the Medical Advisory Panel risked a lack of independence and gave rise to a "*false consensus view*" of the members who were also part of the Centre Directors' Organisation.**

34. I do not recall any specific examples.

- **Please describe how the purpose, function and responsibilities of the Medical Advisory Panel changed (if at all) after this review. Please explain whether Terms of Reference came into being [see** HSOC0010470**].**

35. I do not recall if it changed.

Section 4: Communication and Dissemination of Information by the Society

4.1 Knowledge of risk

- **When you first joined the Society:**

a. **What did you know and understand about the risks of Non-A Non-B Hepatitis/ HCV infection from blood products? What were the sources of your knowledge? How did your knowledge and understanding develop over time?**

36. I only knew what I had learnt from the television or read in the newspaper. I did not know enough about hepatitis C, to be perfectly honest. Sometimes the media can blow things up and not give you the correct information. I learned more as time went on; whilst I was not given any training in particular, I learned a lot more from being on the Executive Committee of the Haemophilia Society.

b. **What did you know and understand about the health implications of Non-A Non-B Hepatitis/ HCV infection during the relevant period? What were the sources of your knowledge? How did your knowledge and understanding develop over time?**

37. When I started on the Executive Committee, I did not really understand the health implications, to be perfectly honest. I knew that Haemophilia sufferers had infected

blood but I did not know what that entailed. From being on the Executive Committee I learned that hepatitis was a potentially fatal disease and could have far reaching consequences for those infected, especially for their liver.

c. **What did you know and understand of the prevalence of Non-A Non-B Hepatitis/ HCV infection amongst haemophiliacs during the relevant period? What were the sources of your knowledge? How did your knowledge and understanding develop over time?**

38. I did not have any knowledge of its prevalence when I first started on the Executive Committee. It increased as I spent more time involved and as general awareness was raised. I knew that several members of the North West Group had been diagnosed with hepatitis, but generally they did not want to talk about it. At a later stage, they opened and started to talk about it on a one to one basis. There were about 300 people in the North West Group. Around the time I joined the Executive Committee, the North West Group had sent out a confidential questionaire. I would say we received around 40, if not more, responses from members declaring they had contracted hepatitis C.

- **In the Minutes of the Executive Committee, on 14 November 1991** [HSOC0010385] **under the subheading 'Hepatitis' it is stated that, "*...the Team had concluded that hepatitis should not be a major concern for the Society. 80% of people infected with HCV and HBV would show no clinical signs and the treatments available were limited; the understanding of the progression of liver disease could only be established through liver biopsies, now considered unethical. The team felt that the Society was in danger of creating concern and worry where they need not exist. Publicity and high-profile coverage would be out of proportion to the threat that actually existed.*" Please can you answer the following:**

a. **Had the Haemophilia Society sought and obtained any advice in relation to HCV before this date? If so please set out who that advice was sought from and what advice was obtained. If it was not sought, please explain why not and please set out the basis for the views expressed in the Minutes.**

b. **Please explain what was meant by "*creating concern and worry where they need not exist*". Please describe, in as much detail as you are able**

and by using appropriate examples, how this conclusion influenced (if at all) the Haemophilia Society's editorial decisions.

c. **How and on what basis did the Project Team and/or the Haemophilia Society conclude that "*[p]ublicity and high profile coverage would be out of proportion to the threat that actually existed*"? Why was the Haemophilia Society concerned about the publicity and media coverage of a Hepatitis C Campaign? [You may also be assisted by** HSOC0023353**].**

39. I do not remember being at this meeting and I do not think I was there. I note that it was on my birthday, and I cannot see myself travelling down to London on my birthday. I do remember that Simon Taylor once said that he would prepare a factsheet to distributed, giving "correct" information as he called it, rather than what was in the media. I am unable to be more precise. I do not know what he meant by "correct" information in the context, and cannot remember when I heard him say this.

- **The Bulletin No.1 – 1994 opened with an article called "***Hepatitis C - A Cause For Concern***" [RFLT0000071]. What prompted the Society to change its position following the Executive Committee Meeting on 14 November 1991 referred to in question 23?**

40. I understand the shift in the Society's position was because it received more information over time. Hepatitis C initially seemed to be overlooked because the Society was more preoccupied with HIV. Over the course of those three years, more information became known about hepatitis C.

41. Around that time, I think we found out that somebody in the North West had died from hepatitis C. Two of us from the North West Group of the Haemophilia Society used to visit Dr Evans at the Manchester Royal Infirmary. When we learned that one haemophilia sufferer had died from hepatitis C, we took this information back to the North West Group. I then raised this with the Executive Committee. This might have been a catalyst for the society changing its view. I do not know if there was other information brought to its attention. I think (but I cannot be certain) that Simon Taylor might have written to the Manchester Royal Infirmary asking why the Haemophilia Society had not been informed about this person passing away.

- **Prior to Bulletin No. 1 - 1994 being published [RFLT0000071], what information and advice did the Haemophilia Society provide to members on the:**

  a. **Risk of Non-A Non-B Hepatitis/ HCV infection from blood products? Please detail the method of communication and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how;**

42. I do not think anything was published. Information that was published went through the Executive Committee, as far as I know, so I would have known about it if it had been.

  b. **Health implications of Non-A Non-B Hepatitis/ HCV infection during the relevant period? Please detail the method of communication and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how; and**

43. As above.

  c. **prevalence of Non-A Non-B Hepatitis/ HCV infection amongst haemophiliacs during the relevant period? Please detail the method of communication and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how.**

44. The only information I had was the confidential surveys I received from the North West Group as already mentioned.

- **Considering your answer to question 25, what was the basis for the communications and advice provided by the Haemophilia Society to members about Non-A/Non-B Hepatitis/ HCV during your tenure? Specifically:**

  a. **To what extent (if at all) were medical professionals relied upon to produce the advice and opinions in these documents?**

  b. **Who provided that advice?**

  c. **Who, and how was it, decided which medical professionals should be approached for any such advice and what advice should be sought?**

d. **Who, within the Haemophilia Society, sought any such advice and who did the medical professional provide the advice to?**

e. **What was their advice in relation to each of the communications you have set out in response to question 25 above?**

f. **If advice was received, was that advice edited? If so, why, and by whom, was it edited?**

g. **Please explain whether the Haemophilia Society also received advice from other medical professionals, what that advice was and, if it conflicted with the published advice, why it was not followed.**

45. This advice would have come from the Medical Advisory Panel. I think Simon Taylor may have had the responsibility of liaising with the Panel. I believe he volunteered. He also got a lot of his information from Dr Christine Lee, who was the Centre Director and his doctor at the Royal Free Hospital. This would have influenced the Society's changing policy towards Hepatitis C. He would take the advice Dr Lee gave him to the Executive Committee meetings. Simon would have given a brief to the committee that was there. Most of the time, seeking medical advice was up to Simon. Sometimes, he would ring Alan Tanner and discuss with him the information that he got from Dr Lee. Then, often before an Executive Committee meeting, Simon would advise other Committee Members to contact their Centre Directors to get their advice, in order to see whether it corroborated the advice Simon had received. My Centre Directors were Dr Wensley and Dr Delamore at Manchester but I was never asked to approach them. The advice that the Society published was never edited. I do not think that we received advice from outside the Medical Advisory Panel.

4.2 Blood Products Policy

- **Please identify the Haemophilia Society's bodies, committees or task groups that were responsible for advising the Haemophilia Society on the safety of blood products.**

46. I cannot recall any committees within the Haemophilia Society tasked with looking at blood products policy.

- **Please detail how the Haemophilia Society's advice on the safety of imported blood products developed during your tenure. What information did the Haemophilia Society communicate to members? How did this information change over time?**

47. Members of the Executive Committee were all against imported blood products. It was not necessarily sent out to the membership that we were against it.

- **To the best of your knowledge, what resources did the Haemophilia Society rely on to evaluate or advise on the safety of imported blood products? In your answer, please provide details regarding the involvement of medical professionals in the decisions and policies formulated by the Haemophilia Society.**

48. Information or advice would come from the Centre Directors, but I cannot remember well enough to say with certainty.

- **To what extent did the Haemophilia Society rely (if at all) on communications from pharmaceutical companies for assurances or opinions on the safety of blood products? If so, please provide as much detail as possible on the points of contact in pharmaceutical companies, the advice provided, the issues raised, and how frequent these communications were.**

49. Every time we went to a conference the companies were there with their products explaining to anybody who wanted to know what they considered to be their products safety. We did not rely on this on the Executive Committee. We tended to rely on the Centre Directors for advice.

50. I think some clinicians may have been influenced by their relationships with pharmaceutical companies. Dr Geoff Savidge would go to the pharmaceutical companies meetings and, because he was friendly with these companies, persuaded them to give him trial products, which he received for free. I got the feeling he favoured using these companies' treatments because it was cheaper for him to do so. I was

concerned that, by doing so, he was using his patients as guinea pigs as the treatments weren't the purest. In my opinion, I felt he was using his patients. It was well known and talked about amongst committee member as far as I recall. I do remember discussing this at an Executive Committee meeting, I think in the early 1990s, but I do not know if it had been recorded in the minutes or if he was ever spoken to about it.

4.3 Publications

- **Please identify the members, groups and/or committees of the Haemophilia Society responsible for editing and selecting material for the Bulletin and other Haemophilia Society publications during your tenure.**

51. David Watters, Graham Barker, and Andy Cowe (the editor of publications) were responsible. If anybody wanted anything in particular putting in the Bulletin, they would contact them.

- **Did the Haemophilia Society know of haemophilia clinicians who felt that their views on imported blood products and/or the risks of infection were not being represented or communicated to members of the Haemophilia Society? Please provide details, identifying clinicians where possible and the issues they raised. Please explain when and how you came to know of these alternate views and, once you were aware of them, what you did about that.**

52. I am not aware.

- **Please identify the members of the Executive Committee and/or committees of the Haemophilia Society responsible for editing and selecting material for the Bulletin, Haemofact and other Haemophilia Society publications during your tenure.**

53. Andy Cowe was responsible.

- **In his evidence to the Penrose Inquiry, Chris James, Chief Executive of the Haemophilia Society, stated that, *"the activities of the Society in disseminating information to its members were often spearheaded by haemophilia doctors"***

[PRSE0000851, page 3]. Do you agree with this statement? If so, please provide details identifying doctors where possible and detailing their activities in disseminating information to the Society's members.

54. I agree with that statement, but I cannot remember which doctors in particular.

- **To what extent, if any, did haemophilia centre directors and members of the Medical Advisory Panel assist in proposing and/or editing and/or selecting material for the Haemophilia Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).**

55. They did not have any direct input. They would have to go through the Executive Committee or Chairman.

- **To what extent, if any, did representatives of pharmaceutical companies assist in proposing and/or editing and/or selecting material for the Haemophilia Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).**

56. They did not have an input.

- **How did the Haemophilia Society select or identify contributors and interview subjects for its publications? Specifically, in relation to its publications which gave medical and/or other opinions about the safety of blood products and the risk of infection, how were the contributors for such articles identified? What, if any, were the criteria for someone to be able to write an article for its publications?**

57. The membership could submit articles. I do not know how the medical articles were selected or curated. If a Centre Director had something to write, they would send this to the Executive Committee who would then consider whether it went in the Bulletin.

- **To what extent (if any) did the Haemophilia Society verify medical and scientific information and/or opinions provided by contributors to its publications? If verification took place, please describe the process by which this occurred.**

58. Andy Cowe and Simon Taylor tended to vet the article. To a certain degree, they would decide whether it went in. If they were unsure, then it would go to the Executive Committee for their opinion.

- **Did the Haemophilia Society receive direct inquiries from the public or members who required advice with regard to the safety of blood products? If so, how were these queries handled? Who would respond? What resources (if any) did the Haemophilia Society rely on to enable a response? Please set out specifically, to the best of your knowledge, what advice and/or information the Society had and from whom that had been provided.**

59. As far as I am aware, there was no mechanism for approaching the Society directly. If someone called asking for advice, the Society would refer them to their local Centre Director. David, who answered the phones, did know an awful lot. But if there was anything he was not sure about, then he would refer them to the centre director.

4.4 Communication to Healthcare Professionals

- **Please detail any activities the Haemophilia Society conducted with the purpose of disseminating information to healthcare professionals during your tenure. If this changed over time please detail when and why.**

60. I cannot recall.

- **In a memo entitled, "Medical Advisory Panel" authored by the Haemophilia Society's Project Team, dated April 1991, it is stated that, *"Society's lobbying might be more effective if endorsed by a Medical Advisory Panel. Politicians, civil servants, health professionals, staff in smaller Centres and some patients might fall into this category"* [underlining added] [HSOC0010277]. To the best of your knowledge, did the Haemophilia Society lobby health professionals and/or staff in smaller centres during your tenure at the Society? If so, how and for what purpose?**

61. I do not know.

- **In the Minutes of the Boarding Trustee Meeting held on 9 May 1996, *"it was reported that the Medical Advisory Panel was critical of the section in the Society's Hepatitis report that contained recommendations for action by Centres. It was felt that it was inappropriate for the Society to comment on the services and treatment provided by Centres as this was a matter of clinical judgement. Some felt that it was wrong for the Society to interview their patients"*** [HSOC0029689_004]. **Please comment.**

  a. **Were there other circumstances in which the Haemophilia Society did make "*recommendation for action by Centres*" or seek to influence UKCHDO policy and practices?**

62. Yes, this is the sort of thing that the Society would do, but I cannot recall any specifics.

  b. **To the best of your knowledge, why did the Haemophilia Society interview "*patients*"? Were there other circumstances in which the Haemophilia Society would interview patients? If so, please provide details as to the purpose of these interviews.**

63. No. If it took place, this is probably something that was decided without the Executive Committee's input, at least in its full capacity. There might have been informal impute through the Chairman or Vice Chairman which may well have been done over the phone.

Section 5: Pharmaceutical Companies

5.1 Financial Relationships

- **To what extent did the Haemophilia Society rely on financial contributions from pharmaceutical companies manufacturing and/or supplying blood products? In your answer, please provide as much detail as possible on any of the Haemophilia Society's activities, publications, appointments and staff that were funded or partially funded by financial contributions from pharmaceutical companies. Please describe the level and nature of funding that was being provided when you commenced your tenure at the Society and how that changed, if at all, over time.**

64. The Society did rely on pharmaceutical companies. I should say for about 1/3 of its funding. The pharmaceutical companies funded a lot of conferences, such as the national conferences. I do not know whether the funding increased. It was definitely not contingent on anything.

- **Was the Society's relationship with BPL different to its relationship with the pharmaceutical companies? If so, please explain how.**

65. It was no different to my knowledge.

- **How were financial relationships with pharmaceutical companies formed? Who prompted these relationships? Who were the points of contact? Please provide details on the method of communication between the Society and pharmaceutical companies for the purpose of receiving/seeking financial contributions.**

66. I was not on the finance committee, so I do not know the answer to this question. This was the domain of Nicholas Lawson, who was the treasurer.

- **How, if at all, did the Haemophilia Society's fundraising activities develop over your tenure? What factors or activities, if any, contributed to increasing or decreasing financial contributions to the Haemophilia Society from pharmaceutical companies manufacturing and/or supplying blood products?**

67. I cannot say as this was not my domain. Locally, if something was needed by one of the medical units, the membership fund-raised to buy it. There was no help from the National Society and no locally raised money was ever sent to the centre.

- **Please explain any differences in the Society's relationships with the different pharmaceutical companies. For example, were there some pharmaceutical companies that donated more, in terms of frequency and/or amount, than other pharmaceutical companies, to the Haemophilia Society? If so, which ones? Did they have different expectations of the Society? Did they want to fund different activities or functions?**

68. I remember that the Haemophilia Society had relationships with Armour, Baxter, Lister and BPL. Perhaps some others. I think communications with these companies would be by telephone with the treasurer. There would always be a finance meeting before the Executive Committee meeting and the balance would be presented to the Executive Committee.

69. Representatives from these pharmaceutical companies would attend the Haemophilia Society National Conferences and they would be asked to speak about their blood products. The Pharmaceutical companies funded the Conferences and they would mingle with the guests afterwards. There would always be a buffet and drinks laid on and sometimes these would be weekend affairs.

70. I do not know whether the amounts of funding differed between companies. I do not think that any one company held more influence than others. I remember Baxter being the biggest contributor in size. I do not think any donated more frequently than others.

- **What, in your view, were the motivations or expectations, if any, of pharmaceutical companies who donated to the Haemophilia Society? Was there an expectation that the Haemophilia Society would provide anything in return and if so, what?**

71. I think that the only expectations of the pharmaceutical companies were that they were allowed a stall at our conferences. I do not think they held any expectations beyond this. I do think they were donating to the Society in the hope that the Society would raise their profile among the haemophilia community.

- **To what extent, did the Haemophilia Society, through its activities and functions, attempt (if at all) to assist pharmaceutical companies to promote their products and/or public image? If so, please provide details, specifying the pharmaceutical companies, the products, the Haemophilia Society's activities and functions, and the way in which these activities and functions promoted the pharmaceutical companies products and/or public image**

72. Not at all, to the best of my knowledge

- **Did the Haemophilia Society publish or disseminate any articles or publications in exchange or with the expectation of receiving financial contributions, or any**

other benefit, by pharmaceutical companies? If so, please provide details on the nature of these articles or publications.

73. The Society used to put a little acknowledgement box in the publications which were funded by pharmaceutical companies.

- **Did the Haemophilia Society refrain from publishing or disseminating any articles or publications in exchange or with the expectation of receiving financial contributions, or any other benefits, from pharmaceutical companies? If so, please provide details on the nature of these articles or publications.**

74. No.

5.2 Other relationships

- **Did the Haemophilia Society rely on pharmaceutical companies for assistance or support, other than financial contributions? If so, please provide as much detail as possible on the support provided, the specific activities/functions that pharmaceutical companies supported, and the names of pharmaceutical companies involved.**

75. No.

76. **What relationship did the Executive Committee-members of the Haemophilia Society have with pharmaceutical companies? Did any representatives of pharmaceutical companies join the Haemophilia Society, either while they still worked for the pharmaceutical company or after they had left?**

77. I am not aware of any specific relationships nor of anyone joining the society who was connected with the pharmaceutical companies.

- **To what extent did the Haemophilia Society rely (if at all) on communications from pharmaceutical companies for assurances or opinions on the safety of blood products? If so, please provide as much detail as possible on the points of contact in pharmaceutical companies, the advice provided, the issues raised, and the frequency of these communications.**

78. I do not think that they did. As I said earlier we relied on the Centre Directors.

Section 6: Relationships with Government

- **Please detail the Haemophilia Society's relationships with the Government and individuals in public office. Who were the main points of contact? How were these relationships formed? Were there regular meetings?**

79. I cannot remember any. David Watters may have had relationships at government level.

- **Please describe the extent of your role and involvement with regard to the Society's interactions with and representations to the Government. If you attended any meetings with Government ministers and/or civil servants and/or other representatives of the Government, please set out when those meetings took place, with whom, whether meetings were minuted, what were the purposes of the meetings and what was discussed.**

80. I did not have any such involvement.

6.1 Reduction of Risk of Blood Products

- **Please identify who was responsible for determining the Society's position in regard to reducing the risk of blood products during your tenure, including by campaigning for recombinant products?**

81. I cannot recall. David Watters did a lot of the campaigning.

- **What were the key issues that the Society pursued?**

82. I cannot recall.

- **How, when and with whom, was the Society's position relating to reducing the risk of blood products communicated to the Government? If this changed over time, please detail when and why.**

83. I cannot recall.

- **Were any assurances given by the Government in response to the communication of the Society's position? If so please set out what those assurances were, who gave the assurances and when they were provided.**

84. I cannot recall.

- **What decisions and actions were taken by the Society based on information provided by the Government (for example, via heat-treatment and screening of blood donors) during your tenure? If this changed over time, please detail when and why.**

85. I remember heat treated products being discussed, but I cannot recall specifics.

- **Did the Haemophilia Society rely on assurances by the Government or individuals in public office on the safety of blood products? If so, please provide details, identifying how the Society's approach changed because of those assurances.**

86. We relied on the assurances of government that products would be heat treated.

6.2 Campaign for Compensation for Hepatitis C

- **In 1994, the Services Committee considered a proposal by the Hepatitis Committee for a HCV publicity campaign "*whose objective it would be to gain better treatment and care for those infected and financial help from the Government as and when those infected became ill*"** [HSOC0023353]**. Several members of the Committee also disagreed with the proposal on the basis of the publicity that would result from such a campaign. You suggested that "*the Society would have to be seen to be actively dealing with the issue of hepatitis otherwise members such as the Manor House Group may approach the press themselves*". Please explain why members of the Society considered that a high-profile campaign was not yet appropriate. Why was the Haemophilia Society concerned with the publicity that would come from a Hepatitis C Campaign?**

Please explain what your concerns about the Manor House group were. What was your own view as to whether a campaign should be pursued?

87. I argued this because I had already been to the Manor House Group, of which I was a member, and sought its opinion. The members of Manor House Group had all agreed it was necessary to do campaigning as that was how people would learn about the risk of hepatitis C.

88. I do not know why the Haemophilia Society was concerned about publicity. I totally disagreed and did not think their view made sense. The Manor House group were very good, and I supported their assertion fully.

- **When did the Haemophilia Society begin campaigning for compensation for haemophiliacs infected with HCV as a result of contaminated blood products?**

89. I cannot remember exactly when. It was whilst I was on the Executive Committee. I believe it was after that meeting in 1994.

- **What prompted the Society to begin campaigning for compensation for haemophiliacs infected with HCV/HCV as a result of contaminated blood products [BAYP0000010_144; http://www.penroseinquiry.org.uk/preliminary-report/]?**

90. I think it was pressure from the Membership and the Manor House group. There did not seem to be any pressure from elsewhere, such as the Haemophilia Centre Directors Organisation. It came from those who were directly affected.

- **Please identify who was responsible for determining the Society's position in relation to campaigning for compensation for haemophiliacs infected with HCV/Hepatitis C as a result of contaminated blood products.**

91. It would have been whoever was the General Secretary at the time. I think Graham Barker took over from David Watters on an interim basis and had been trained up by him.

- **What was your personal role in relation to the campaign for compensation for haemophiliacs infected with HCV as a result of contaminated blood products?**

92. I sought to make the campaign widespread and continuous, rather than a one-off news story. It is possible that my backing of the Manor House Group at the Executive Committee helped this campaign.

- **What were the goals and priorities of the campaign for compensation for HCV?**

93. We wanted to get compensation for the patients as soon as possible. There was a worry about many dying or becoming too ill before they saw any benefit from the campaign. Furthermore, we wanted to ensure that spouses and partners would be paid if their other half had passed away.

    a. **How were the goals set?**

94. The Executive Committee set the goals, having consulted the membership and appropriate pressure groups such as the Manor House Group.

    b. **To what extent did the Haemophilia Society achieve these goals during your tenure?**

95. I think most of it was achieved. The Manor House Group put an awful lot of pressure on the Executive Committee. There was no compensation paid whilst I was there, but eventually compensation was awarded.

    c. **Were the Society's goals communicated to the Government? Was there a response?**

96. Government relations was nothing to do with the committee. It was more to do with the General Secretary's office. David Watters used to do an awful lot of campaigning for the Society. He was worth his weight in gold. I think that whoever succeeded David Watters would have dealt with later communications with government.

    d. **What statements and assurances were made by the Government to the Society in relation to the compensation during the relevant period? Who**

provided any such statements or assurances? If this changed over time, please detail when and why.

97. The Government made some ridiculously low offers. But it was peoples' lives and futures that were concerned so we did not accept. I cannot remember any particular figures or the names of those involved.

e. **Were these statements or assurances relied upon? If so, how?**

98. No.

- **To what extent (if any) was the campaign for compensation informed by the views of Haemophilia Society membership? Did these differ from the views of the Haemophilia Society, as you understood them?**

99. The campaign's aims were driven by the of the membership, which the Society adopted.

- **What was the Haemophilia Society's position (if any) with regards to compensation for haemophiliacs who were infected with hepatitis as a result of contaminated blood products during your tenure? If this changed over time, please detail when and why.**

100. The Haemophilia Society supported ongoing campaigning for compensation for those who had been infected with hepatitis C through blood products.

a. **Was this communicated to the Government? Was there a response and if so what was it?**

b. **What statements and assurances were made by the Government to the Society in relation to compensation during the relevant period? If this changed over time, please detail when and why.**

101. I am not aware of any such assurances.

c. **Were these statements and assurances relied upon? If so, how?**

102. I am not aware of any such assurances.

6.3 The Supply of Imported Blood Products

- **Please identify who was responsible for deciding the Society's positions and representations made to the Government regarding the use and supply of imported blood products.**

103. David Watters spoke to the government but I cannot say where he got his information and instructions from.

- **Please identify the goals and priorities, during your tenure, of the Haemophilia Society with regards to the supply of imported blood products. What were the key issues that the Society pursued and during what period?**

104. The Haemophilia Society were pursuing its goal that it did not want to rely on imported commercial blood products.

- **Did the Haemophilia Society receive assurances by the Government or individuals in public office on the use and supply of imported blood products? If so, please provide details of the assurances that the Society received, with details of the individual or department that made them.**

105. I am not aware of any such assurances

Section 7: Relationship with MacFarlane Trust

- **Please can you explain why you held the view that 'certain issues at trustee meetings would be inhibited by the presence of an observer who was a registrant'. How did the Macfarlane Trust respond to the request for two registrants to be appointed to its board of trustees by the Haemophilia Society? What was the reason for any existing friction between the Macfarlane Trust and the Haemophilia Society? You may wish to refer to [HSOC0029690_051 at page 4] when providing your answers.**

106.I did not think it is a members' place to be at a meeting like that, because they can take the things discussed out of context and make more out of them than what was said. This impacts decision making in my opinion The Trust did not agree, so there remained observers at the meetings.

- **On your role as a trustee for the Macfarlane Trust, please can you answer the following:**

  a. **For which period were you a trustee, and how were you appointed?**

107.I think I joined in 1993, around two years after I started serving on the Executive Committee. I was asked to join the committee by Reverend Alan Tanner, who was the chair of the Macfarlane Trust.

  b. **Please provide your view as to the efficacy of how the Macfarlane Trust was run during your tenure and whether it achieved its aims and objectives.**

108.I can only say that I think it achieved all its aims and objectives but I cannot really say how. I think it was a well-run organisation. The Macfarlane Trust Committee made the decisions: some got turned down because they were asking for things that were, to my mind, beyond what the fund could provide, like a new washing machine, rather than things that were directly related to their illness.

109.I think the criteria that the Macfarlane Trust used was fair. We did not want the Trust treated like a money bank and resisted attempts to take advantage of it. I cannot remember who was on the committee of the Trust at the time with me but there were normally around 8-10 members when decisions were made and it was done by a vote

  c. **Were there difficulties or shortcomings in the way in which the Macfarlane Trust operated or in its dealing with beneficiaries and applicants for assistance. If so, please describe them. What, if anything, do you consider the Macfarlane Trust could or should have done differently?**

110. It was not an easy position to be in. I spent hours going through the applications each month and I had to make some difficult decisions but I always did what I thought was right under the terms of the Trust. Application were submitted on paper and possibly it would have been useful sometimes to see someone in person but the shear volume of work and the time it took made this impossible. There was an appeals process, but it was difficult to add additional information which could change the Trust's mind. I have been asked if we were ever told about financial constraints but that was never the case. I did not know what the budget was but I could have asked Nicholas Lawson as he was Treasurer of the MFT as well as National Society.

Section 8: Other Issues

- **Please explain, in as much detail as you are able to, any other matters that you believe may be of relevance to the Infected Blood Inquiry, having regard to its Terms of Reference and to the current List of Issues.**

111. I have nothing further to add that would assist the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 27- 4 2021