Witness Name: Jonathan Cooper
Statement No: WITN4503001
Exhibits: WITN4503002
Dated: 25 February 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JONATHAN COOPER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 November 2020.

I, Jonathan Cooper, will say as follows: -

Section 1: Introduction

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

1. My name is Jonathan Paul Cooper. I was born on GRO-C 1962. I live in GRO-C GRO-C Devon GRO-C. I am a barrister and I practice international human rights law from Doughty Street Chambers. I attach a recent CV which contains my employment history **[Exhibit WITN4503002]**. I was employed between 1987 and 1990 as the AIDS Co-ordinator for the Haemophilia Society (THS). This was my first job on leaving university in 1987.

2. It is important to stress from the outset that many of the detailed questions that have been flagged up by the Inquiry raise issues that were well and truly outside of my areas of work and/or expertise at THS. The detail of some issues raised I simply cannot recall, although I remember much of what happened.

3. The Inquiry has addressed a number of specific questions which, even though I recall the events, I am not in a position to provide an adequate response. I would be guestimating with the benefit of hindsight and, in my opinion, that would not be in the interests of the Inquiry. If the Inquiry would like me to respond to each question, I am happy to do this, although my answers will be that I cannot recall that level of detail.

4. By way of introduction I also think it is important to point out to the Inquiry, that THS in the 1980s was a classic voluntary sector organisation of its time. It was essentially run by volunteers. It was there to provide mutual support to those affected by haemophilia and associated issues. Hepatitis and HIV became included in those associated issues.

5. Professional support was brought in and, but for the viruses, THS would likely have remained a small healthcare charity servicing the needs of the small haemophilia community in the UK.

6. The trustees were remarkable people. Many of them still recalled the days before Factor 8, when their childhoods were marked by long periods of bedrest to control bleeds and all the associated pain linked with haemophilia. Many of them had spent time in the same school which specialised in managing haemophilia (amongst other conditions). They were fighters and survivors. There was a lot of humour – gallows-type humour. They also knew each other well.

7. These people were the beneficiaries of one of the great post war medical revolutions. Their lives became normalised. Pain became the exception and not the rule. And then the blood borne viruses came along.

8. By 1987, when I started to work for the Society, they had already gone through the first wave of hepatitis viruses. HIV/AIDS had become part of their everyday lives. They were not victims. They continued to be fighters and survivors, but they were weary. I compare them with a group of mighty warriors, who would still pick themselves up and be ready to fight the next battle. The Revd Alan Tanner offered wise leadership and men like Ken Milne were like great, experienced Generals. Ken knew exactly how to mobilise his forces, and they all cared so deeply about all people with haemophilia.

David Watters was a loyal Colonel. He took his orders and went back into battle for them.

9. It was interesting to be reminded of the names of the Management Committee for 1988. Within years, so many would be dead. If they didn't die, their husbands or children did. It was an extraordinary time and one which I got a unique insight into. The health care professionals had gone from transforming the lives of people with haemophilia to infecting them with terrible viruses. Witnessing those evolving relationships between patient and clinicians was equally extraordinary. But what was not in any doubt in my mind, was the conviction that all involved were driven by public service. Ensuring the best interests of all people with haemophilia was what motivated them.

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.**

10. I have not provided any evidence nor have I 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 6 virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products.

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

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

- **Please describe how the organisation was structured, including the governance arrangements and the day to day management and running of the Society. If this changed over the period of your tenure, please set out those changes.**

- **Please describe the relationship between the Board of Trustees, Council, Executive Committee and the day-to-day management of the Society.**

- **Please explain the dynamics and hierarchy of the staff and trustees at the Society. Please include (a) the formal and informal line management arrangements, (b) the decision-making structures and (c) whether any staff or trustee had particular influence over decisions of the Society.**

- **Please set out what your role entailed, how you came to be appointed to it and how the role was funded [HSOC0019591 may assist].**

11. I was employed as the AIDS Co-ordinator for THS in 1987. My line manager was David Watters, the General Secretary. David is/was (he's now retired) a charity sector professional. He ran a well organised ship and he expected high standards of himself, the trustees, the staff and volunteers. He was an excellent first boss and he instilled in me a strong workplace ethic.

12. We were a small – tiny – organisation and David knew everything that was going on. Rightly, he considered the trustees to be his responsibility and he kept trustee governance at arm's length from the staff, but the trustees were involved in the everyday work that went on in the Society.

13. I had close associations with two trustees, Andy Cowe and Caroline Hazelwood, and they were very involved in my work. David was my line manager, but Andy and Caroline led on various projects. I also had close links with Clive Knight who was always interested in what I was working on, and Julian Miller I would describe as an ally. There were others involved, like GRO-A, who may not have been a trustee, but he was directly involved in THS's work. Ken Milne also followed my work closely.

14. The trustees, staff and volunteers felt like one team. Alan Tanner was a wonderful chair. As far as I could make out, Alan and David had a good working relationship, which is the heart of any successful organisation.

15. David had deep respect for Alan and David was deferential to the trustees. He was always clear that the trustees were his boss and before a trustee meeting, he prepared thoroughly. He was clear to the staff that we should show the trustees the same level of deference and respect.

16. Policy issues were always left to trustees. Nothing substantive would happen within THS without their sign off. David was meticulous about minuting issues and leaving a paper trail.

17. I had friendly relations with all the trustees. I worked most closely with Andy, who was a very fine person to guide my work.

18. This was my first real job and therefore I was on a very steep learning curve. I learnt a lot and I remain very grateful to them all.

19. The staff also worked cohesively. Linda knew everything that was going on in the world of haemophilia. I had to earn her respect, but once I did, she was a delight to work with. She was highly organised and professional. Heather was probably a bit vulnerable. She was highly intelligent and much more capable than her job description. Jean was a delight and she filled the office with laughter and light. Jude and Alan were quiet and efficient and nice company. After a couple of years GRO-A took over much of the administrative side. He was perfectly competent, but less of a team player. My recollection is that Jean and then Heather left. It was a nice team to be part of. It felt a safe place to work. David was our boss and below him the structure felt flat. We all answered to him. If there was a hierarchy amongst us, it was not noticeable (or important).

20. The work was fascinating and rewarding and I was well supported.

21. The members were the key to the organisation. The membership always remained THS's priority. We were there to serve them. Linda was absolutely on top of the membership, which probably meant she was the next most important staff member after David. She and David knew everyone. It was really impressive to observe them with the membership and listen to them deal with membership issues. At that time, I think most people with haemophilia were members of the Society, certainly those with severe haemophilia.

22. The Society's function was to support its members and all people with haemophilia. It therefore engaged with all aspects of living with haemophilia, particularly in relation to healthcare, but most issues from schools to social services were part of THS's remit. And, then, of course HIV/AIDS also became central to what THS did.

23. HIV/AIDS was overwhelming the Society. They therefore fundraised and secured funding for the position that I was to be appointed to.

24. People with haemophilia knew all about AIDS. I learnt from them. David had also been forced to become an expert. Linda had a science background and she too was an authority.

25. The majority of the trustees were either living with HIV or their partners or children were. My role was to manage the HIV specific aspects of what the Society did. It goes without saying, as a recent history graduate, I was unqualified for the job, but back then no one wanted to work in HIV. The position was advertised in the Guardian. It was the first job I applied for on graduation. I recall there was a two-interview process. Remarkably (to me and my mother), I got the job. I hit the ground running and had a steep, exponential learning curve. David was indispensable for that. He was wise and thorough in his induction of me. I also spent large amounts of time in the Haemophilia Centre at the London Hospital.

26. My recollection is that at some point David informed me that he'd secured funding to ensure my role would be permanent. I had no role in fundraising other than for a few specific projects.

27. A lot of what I did was delegated to me by David. I became THS's outward facing link with haemophilia and HIV. David literally didn't have time to do everything. I also supported David in his work. I kept him, and therefore THS, up to speed on HIV related issues from treatment to prevention. I worked very closely with him on the campaign for recompense.

28. I had various projects of my own. To highlight a few, these included explaining the benefits system for HIV, co-ordinating the first symposium on paediatric HIV and producing the first safer sex guide focussed on people with haemophilia. I also worked with HIV organisations on establishing a respite system for people with HIV/AIDS, drafting the Declaration of Rights for People with HIV/AIDS and developing systems of complimentary therapy for those who wanted it. There was a big demand.

29. I also monitored the Haemophilia Centres – a principal focus of that work was assessing how well HIV was managed within Haemophilia Centres.

30. In my last year at the Society, I was also seconded to the World Federation of Hemophilia. I drafted their materials on living with haemophilia and HIV. This meant that I would travel to Montreal (where it was based) and to Calgary, where a social worker that I worked with lived.

31. We were always having to respond to immediate issues. These could arise from the campaign for recompense, a news item or something like the US Government imposing a travel ban on people with HIV entering the USA.

32. My role was to give effect to THS's agreed policy linked to HIV/AIDS. My input was always welcome, but the trustees made the policy, not the staff. On issues relating to haemophilia treatment, I would have little or no involvement although I would be aware of the discussions. The trustees were the experts. To the extent that THS took a position on HIV treatments, David and I would offer our understanding of those treatments.

3.1 Committees and Advisory Bodies

- **Please list all the different committees and advisory bodies that you recall were set up within the Society.**

33. I was not involved in any decisions to set up committees, panels or advisory bodies. My recollection is that Andy Cowe chaired the sub-committee(s) that oversaw my work. I was answerable to Andy, but responsible to David. It is also my recollection that we would set up ad hoc panels to deal with particular projects such as the safe sex guide or the Declaration of Rights. These might just have one or two people on them. Andy, I know, oversaw the safe sex guide (which went on to win the HEA/Domestos health education award).

34. I think Ken had responsibility for the Declaration. I recall that it was Ken who led the calls for a boycott of the USA when the Bush Snr administration introduced a ban on people with HIV entering. The global boycott of the USA by those affected by HIV began in the UK's Haemophilia Society. The Declaration contained a right to free movement. Ken's view was that we either believe in the Declaration or we don't. If we do, we cannot countenance this arbitrary interference with free movement rights.

3.1.1 The Medical Advisory Panel

- **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.**

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

- **In a letter to Dr Ludlam dated 8 August 1988, David Watters stated that "The Medical Advisory Panel has, until now, not played a major part in the life of the Society. However, it is the clear wish of the Executive Committee that this situation should change." [HSOC0011023] Please explain the role of the Medical Advisory Panel up to 1988. Specifically:**
  - **a. How was advice sought from the Medical Advice Panel?**
  - **b. Who decided when and on what matters advice would be sought?**
  - **c. Was advice sought from all members of the Medical Advice 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 Advice 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. How was advice communicated from the Medical Advisory Panel to the Society?**
  - **g. How was the Panel's advice recorded once it was received by the Society?**
  - **h. In relation to what issues relevant to the Inquiry's Terms of Reference did the Haemophilia Society seek the advice of the Medical Advisory Panel?**

- **From 1988, how often did the Medical Advisory Panel meet? Who attended those meetings in addition to the members of the Panel? The Inquiry is aware that you attended some of the meetings of the Medical Advisory Panel [HSOC0010954], what was the purpose of your attendance?**

- **Why did the Haemophilia Society decide that the Medical Advisory Panel should meet in person? Please describe how the role of the Medical Advisory Panel changed over time from 1988. Specifically:**
  - **a. How was advice sought from the Medical Advice Panel?**
  - **b. Who decided when and on what matters advice would be sought?**
  - **c. Was advice sought from all members of the Medical Advice 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 Advice 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 Haemophilia Society seek the advice of the Medical Advisory Panel?

- **What happened when members of the Medical Advisory panel disagreed with each other? What approach did the Haemophilia Society take to resolving any such disagreements? Who decided which advice should be followed? How did they do that?**

- **As far you can recall, please describe:**
  a. To what extent 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.
  b. All examples, relevant to the Inquiry's Terms of Reference, of when the Haemophilia Society did not follow the Medical Advisory Panel's advice;
  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;
  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.

35. I had minimal involvement with the Medical Advisory Panel. I would work with individual Haemophilia Centre staff and these people might be on the MAP. I cannot recall what happened to my reports on individual Haemophilia Centres. My reports would be signed off by David and Andy. I do not recall if these reports were sent off to the MAP.

36. I do not recall the specific details of why I advocated for the appointment of a health care professional. The late '80s/early '90s were a transformational moment for the civil society sector. The voluntary sector had become the NGO sector. Charities had become professionalised. In health charities there was less deference to medics and

the consultants. I recall that our colleagues in the US equivalent of THS, the National Hemophilia Federation, included medical expertise. My view was that we should become more like them.

37. The treatment experts within THS were the trustees. They would seek advice from numerous sources. David could also hold his own, but I believed expertise from within the Society could only have been a good thing.

38. Some Centre Directors played a bigger role in the Society than others, but that did not necessarily mean they had more influence on the policy decisions the trustees took. Trustees like Clive, Ken and Andy knew exactly how to evaluate evidence and the weight to attach to it.

3.2 Interaction with Other Organisations

- **What was the Society's role and involvement with the UK Haemophilia Centre Directors? What was the function and role of the Haemophilia Society's committee-members attending the Regional Meetings of UK Haemophilia Centre Directors during your tenure?**

- **What was your role and involvement in the Management Committee of the Disability Alliance? What issues did you raise during your tenure? Did members ask you to raise particular concerns? If so, what were they and did you raise them at Committee meetings? What response did you receive? [RFLT0000091 may assist].**

39. With regret, I cannot recall what the Society's role and involvement with the UK Haemophilia Centre Directors was.

40. As a trustee of the Disability Alliance, I was concerned about access to benefits and social security. It was my work on welfare benefits that had led me to become a trustee of the DA.

Section 4: Communication and Dissemination of Information by the Society

4.1 Publications

- **Please detail the publications that the Haemophilia Society sent out to its membership during your tenure. Please describe the frequency with which each**

type of publication was disseminated and whether they were all sent out to all members of the Society. If this changed over time please detail when and why. The Inquiry is aware of:

  a. The Bulletin;
  b. Group Seminar Proceedings;
  c. Haemofact; and
  d. C Issues.

- **To what extent, if any, did haemophilia centre directors and members of the Medical Advisory Panel assist in editing and selecting material for the Haemophilia Society's publications?**

- **To what extent, if any, did representatives of pharmaceutical companies assist in editing and selecting material for the Haemophilia Society's publications?**

41. My memory is that Andy had editorial responsibility at THS. All publications would go through him. Other than specific projects, such as the safe sex guide, David would feed copy to Andy. I do not recall editorial policies, but Andy would have the last say. I do remember different people would be asked to write for the Bulletin. I don't think that being published by the Bulletin was an official THS endorsement of what the author said.

42. The Society was very careful and risk averse. I would be very surprised if science and facts weren't checked. I wouldn't be surprised if Bulletin articles would have been peer reviewed. I expect they were, but I do not know. The MAP would not have had a role in the process.

43. Multiple copies of the Bulletin were sent to all Haemophilia Centres. There was a general expectation that all involved with and affected by haemophilia would read the Bulletin. There were also sensitivities. Links with haemophilia and HIV could cause stigma. THS was sensitive to these concerns but did not shy away from trying to get people information who wanted to receive it.

44. The received wisdom was that THS, as well as people with haemophilia more generally, understood the basics of HIV, along with other blood borne viruses. There was an expectation that information would have been given by individual Haemophilia Centres and there had been one-off leaflets from THS as well as articles in the Bulletin.

45. It was expected that health care professionals would play a leading role in providing information to people with haemophilia and, where appropriate, their families. However, the principal provider of that information may not be the doctor. There was a recognition that all within the Centre may play a part, which is why THS focussed as much on nurses, social workers and counsellors as they did doctors.

46. The decision was made to draft the safer sex guide because this was an area that THS considered may not be being adequately addressed within Haemophilia Centres.

47. David dealt with all blood product inquiries, regardless of their source.

48. The whole experience of haemophilia, blood products and blood borne viruses raised multiple ethical issues that just got dealt with. The ethical framework of today was an aspiration back then. THS believed in the highest ethical standards. What position THS took in relation to the particular issue relating to Hep C and being tested without their consent, I do not recall.

49. I also recall events where people with haemophilia would meet up via THS, but I do not recall the detail.

50. In relation to my request for information on HIV related discrimination, I did receive this information from both individuals and also Centres. This information was used to highlight the situation that people with haemophilia lived within. THS was acutely concerned for the welfare of all people with haemophilia and HIV, including their families and sexual partners.

51. I was concerned that Haemophilia Centres may not be the best places for the management of HIV. I discussed this with a number of health care professionals and would definitely have done so with Dr Mark Winter, because he was very engaged with the management of HIV. I do not recall any follow up. My concerns about HIV management within Haemophilia Centres were not mainstream within THS and they may have been unfounded, but THS was prepared to entertain them.

52. These were terrible days when treatment for HIV was in its infancy. Opportunistic infections could be treated on a case by case basis, and although AZT had emerged as an anti-retroviral and there were other drugs, HIV was not controlled. AZT was also controversial.

53. The reality in the late 80s was that a diagnosis of HIV was grim. The prognosis was bleak. The better managed people were, the better their chances. There was a critical

watershed moment when managing infections lost out to the virus. Once that happened, there could be a very fast spiral downwards.

54. It's important to recall that THS was working in that environment. Serious illness and death were inevitable. Even if people recovered from an illness, they didn't get better. I do not recall the exact statistics, but the majority of the deaths were in the early 90s. In the late 80s this was the outcome that we were anticipating. Managing both living and dying with AIDS was increasingly the priority for THS.

55. My question for Haemophilia Centres was how well equipped were they to manage that healthcare? I do not recall the outcome of those discussions. I do recall raising it with NAT, in their role as co-ordinating the NGO sector response to HIV. I am not sure what they did with that information.

56. One of the reasons why we organised the first symposium on paediatric HIV in the UK was to try to encourage national standards.

4.1.1 The Bulletin

- **Please explain how the Bulletin was made available to members and the wider haemophiliac community? What was the Haemophilia Society's knowledge of the extent of the Bulletin's reach within the haemophiliac community?**

- **Please describe how the Bulletin was made available to healthcare professionals. What was the Haemophilia Society's knowledge of the extent of its reach amongst professionals who provided medical care and treatment to haemophiliacs?**

- **Please identify the members and/or committees of the Haemophilia Society responsible for editing and selecting material for the Bulletin.**

- **How did the Haemophilia Society select or identify contributors and interview subjects for the Bulletin? Specifically, in relation to Bulletin articles 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 the Bulletin?**

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

- **When you started work at the Society, what was your personal knowledge and understanding of AIDS and HIV?**

- **When you started work at the Society, what information were you given about AIDS and HIV? Who provided you with any such information? What was the source of such information? What was the Society's understanding of the likely impact of HIV on people with haemophilia? (It may be useful to consider [HSOC0029599] and [PRSE0006087, page 124, §9-13]).**

57. See above

4.2 Other Communication

4.2.1 Communication to Members

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

- **Please set out the dates, locations, speakers and content of presentations for all residential seminars that were held during your tenure.**

- **Please confirm which seminars resulted in a report, that is a Group Seminar Proceedings paper. Please explain to whom such reports were disseminated.**

- **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.**

- **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.

- During your tenure, what information and advice did the Haemophilia Society provide to members on the:
  a. risk of Hepatitis Non-A Non-B/Hepatitis C 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;
  b. health implications of Hepatitis Non-A Non-B/Hepatitis C 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
  c. prevalence of Hepatitis Non-A Non-B/Hepatitis C 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.

- Considering your answer to question 36, what was the basis for the communications and advice provided by the Haemophilia Society to members about Hepatitis Non-A/Non-B/Hepatitis C 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 answer to question 36 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.

- **When the Medical Advisory Panel met on 27 April 1990, it was noted at paragraph 7d that "A number of people are known to be Hepatitis C positive from blood tested from stored samples. This brought up the old ethical dilemma of how to inform people of a test result that they have not asked for" [HSOC0010954]. What was your understanding of this situation? What did the Haemophilia Society do in light of this knowledge? Did the Haemophilia Society communicate this information to its members? If so, please set out when and provide copies of the relevant publications and or letters. If not, please explain why not.**

58. See above

4.2.2 Communication from Members

- **In the Bulletin in 1988, you requested that members write to the Society about their experiences if they had been discriminated against on account of HIV/AIDS [PRSE0002224]. What response did you receive? Was a report written compiling the experiences? If so please provide a copy to the Inquiry. What actions did you take having compiled the responses?**

- **In the June 1990 minutes of the Policy Committee, you are reported as liaising with the NAT about improving standards of HIV Care within Haemophilia Centres [HSOC0017204]. In addition, you wrote "A Proposal for examining the standards of HIV care within Haemophilia centres" [HSOC0017280].**
  a. How did this issue arise? Did members raise with the Society concerns about the quality of HIV care that they were being provided with?
  b. It appears that you wrote the proposal with Dr Mark Winter. How did Dr Winter come to be involved in the proposal?
  c. The minutes also record that it was suggested that "it should be Society policy to recommend that people with haemophilia have the HIV managed outside of their Haemophilia Centre". Please explain why this was suggested and whether there were specific concerns about particular Haemophilia Centres or whether it was a generic concern.
  d. What was the result of your liaising with NAT?
  e. The minutes record that you were to "express Society concerns to Dr E Mayne" as the Chair of the UKHCDO. Did you raise any concerns with Dr Mayne? If so, what matters did you raise? What was her response? How did these matters progress, if at all?

f. Was the proposal accepted within the Society? If so, what happened thereafter? If not, why was it not?

59. See above

4.2.3 Communication to Healthcare Professionals

- **Please detail any other 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. See above

Section 5: Relationship with the Government

- **Please identify the extent of your role and involvement with regard to the Society's representations to the 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?**

61. I supported David in his work with Government. David had direct contact with central Government and the then DHSS. I worked closely with backbench MPs and members of the House of Lords. Our links with MPs tended to come via their constituents. This was particularly the case with Robert Key MP and Frank Field MP.

62. An example of what my work might entail, at one point there was concern that the (now) EU blood product supply could be affected by new EEC Regulations. I was sent off to lobby MEPs and request that they engage with their local haemophilia communities.

5.1 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?**

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

- **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.**

- **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.**

- **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 Haemophilia Society's approach changed because of those assurances.**

63. The trustees were responsible for determining the Society's position in regard to reducing the risk of blood products. David would act on their instructions. I do not recall the precise detail of that policy, but David would regularly meet and interrogate people from BPL and pharmaceutical companies. He would also meet with the DHSS. I do not recall the detail.

5.2 Campaign for Compensation

- **When did the Haemophilia Society begin campaigning for compensation?**

- **What prompted the Society to begin campaigning for compensation for haemophiliacs infected with HIV/AIDS as a result of contaminated blood products [BAYP0000010_144]?**

- **Please identify who was responsible for determining the Society's position in relation to campaigning for compensation. Please explain your role in (a) determining the Society's position and (b) implementing those decisions.**

- **What were the goals and priorities of the campaign for compensation? How were the goals set and by whom? Who decided upon the strategy to achieve those goals?**

- **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 Executive Committee, as you understood them?**

- **The Inquiry understands that shortly after you took up your post, the campaign was launched and literature was produced that was sent to the Haemophilia Centre Directors [RHAL0000213]:**
  a. **Who produced that literature?**
  b. **What did it contain? If you have a copy of it, please provide it to the Inquiry.**
  c. **What was the response, if any, from Haemophilia Directors? Please set out the differing responses, what was said and by whom.**

- **On 23 October 1987, you wrote a document entitled "Aids and Haemophilia: The Hidden Disaster" [HSOC0004680]. Please explain why this document was written. Was it disseminated in any way? If so, please set out how it was disseminated, when and to whom it was disseminated.**

- **When the Society met with John Moore on 4 November 1987, who attended the meeting? What was discussed? Was the Society given any assurances at that meeting? If so, what were they? Did the Society change their strategy and/or actions in reliance on any of those assurances? [HSOC0013021, HSOC0022966 and HSOC0004740 may assist].**

- **The Inquiry understands that there was a meeting of Parliamentarians on 5 November 1987 [HSOC0003584]. Who arranged that meeting? Who was invited to attend? How were those individuals chosen to be invited? Which members of the Society attended the meeting? What was discussed? Was the Society given any assurances at that meeting? If so, what were they? Did the Society change their strategy and/or actions in reliance on any of those assurances?**

- **Shortly after the meeting, you wrote to attendees asking them to put questions for the December Social Services question time [HSOC0004759]. What response did you receive to that request? Please set out what took place thereafter.**

- **Were there any other meetings with Members of Parliament and/or of the House of Lords in late 1987 regarding the campaign? For example, was there a further meeting with Lord Irving? [HSOC0004662]. If so, please set out who the Society met, whether yourself personally and/or other staff members of the Society; when and what was discussed.**

- **Were there any other meetings with Members of Parliament and/or of the House of Lords from 1988 regarding the campaign? If so, please set out who you and/or other staff members of the Society met; when and what was discussed.**

- **To what extent (if any) did the Haemophilia Society achieve the goals set out in your answer to question 52 above, during your tenure?**

- **Insofar as you have not answered these questions elsewhere in your response, please explain:**
  a. Were the Society's goals communicated to the Government? Was there a response?
  b. What positions and assurances were made by the Government to the Society in relation to compensation during the relevant period? Who provided any such assurances? If this changed over time, please detail when and why.
  c. Were these assurances relied upon? If so, how?

64. THS launched a Campaign for Recompense just after I joined. My role was to give shape and continuity to that campaign. It was designed by Simon Taylor, a professional comms person GRO-A. We got advice from leading figures in lobbying and campaigning. David was pivotal but Simon devised a brilliant campaign which worked on multiple levels.

65. The Society had received legal advice that litigation was unlikely to succeed and that THS would not be able to co-ordinate some kind of class action. THS therefore decided to pursue a different strategy. These decisions had been made before I joined.

66. Arguably, the decision to pursue recompense (and not compensation) was a defining moment for THS.

67. The campaign for recompense was successful and brilliantly executed. I claim no credit. I just did what I was told. I drafted letters, documents and articles. I created databases and contacts. The thrust of the campaign was the additional costs associated with living with HIV/AIDS on top of haemophilia.

68. THS had enlisted the support of some health care professionals who gave examples of the added costs of living and dying with AIDS on top of living with haemophilia. I recall we produced detailed budgets. My memory is that the Newcastle Centre played

a prominent role, but so did other Centres across the country. I recall the haemophilia nurse in Leeds was actively involved.

69. It was a top-down strategy, but local groups and local members were kept in the loop. People with haemophilia were encouraged, if they wanted to, to speak for themselves. But the ever-present priority was protecting confidentiality. My recollection is we took the Society logo off the stamp/franking machine so that mail linked to haemophilia couldn't be identified.

70. Different people came forward to speak with the press. We supported them in that process.

71. The position of THS was that people had received treatment from the NHS which had given them a debilitating, likely fatal condition. The case put by THS wasn't one of negligence. We avoided all suggestions of fault and victims. The Society argued there was a moral obligation on behalf of the Government. 1200 people had turned up for treatment in good faith, the result of which was they were exposed to fatal illness. Stripped of law, it is a compelling argument.

72. Effective treatment for HIV was a distant dream. People with haemophilia and HIV needed help now.

73. During the run up to the launch of the campaign we had many meetings. I do not recall what was agreed at those meetings. The Government was put under pressure from multiple sources: the media, Parliament, civil society and the great and the good. David would liaise with national and international media. I would speak to local media and independent journalists.

74. The campaign was too successful. It achieved its objective of the recognition of the situation that people with haemophilia found themselves in within days. The Government offered to set up a trust fund for people with haemophilia and HIV and offered a one-off *ex gratia* payment of £10 Million pounds. I do not recall the terms of the offer.

75. I have views on that process now. I do not believe the Government gave the issues sufficient thought and we have lived with the consequences since, but these views aren't relevant to this Inquiry.

76. The discussions about whether to agree to take the offer were intense. It was decided to accept it. "It was a start", said Alan Tanner. All the trustees were involved. It was a collective decision. I recall Clive Knight and Alan Tanner were deeply immersed in the campaign, but the person who spearheaded the whole campaign was Simon Taylor. Amongst other issues, there was a concern that if THS did not accept it, we might lose the support we had gained.

77. The Campaign for Recompense quickly transformed into the Macfarlane Trust and the added costs of living with HIV were picked up by that Trust.

78. I recall the "Hidden Disaster" document. It was just one part of the campaigning materials. I recall THS having done what it could to consult as widely as it could in relation to the campaign, within the haemophilia community and amongst haemophilia health care professionals.

79. With regret I do not recall all the meetings that were held. David and Simon were clear that this was not a party-political issue. They kept the focus tight. Recompense was a moral duty on the part of the Government. Living with AIDS on top of haemophilia imposed an impossible burden on individuals.

80. We were also clear that the welfare system (as it then functioned) had reached its maximum ability to support people with haemophilia who were dependent on benefits. The additional costs of living with AIDS meant that people with haemophilia and HIV were in effect disadvantaged within the welfare system. Because of the links between disability and poverty (particularly inherited conditions passed down through families), HIV, we pointed out, had a disproportionate impact on people with haemophilia, which the benefits system was not equipped to cope with.

81. MPs were responsive to these issues. I assume questions were raised with the DHSS, but I do not recall the outcome.

82. As a consequence of the campaign, people with haemophilia and HIV had access to some resources to help them live with HIV/AIDS. And the received wisdom at the time, was that people with HIV had a limited life span. It was a brilliant campaign, but with the benefit of hindsight, whilst it succeeded in achieving what it set out to achieve, was it the right strategy?

83. To answer that question, you have to go back to the mid-'80s and address the very real challenges that people with haemophilia and HIV faced. The legal advice THS had received was clear. Litigation was a non-starter. In the light of that and the reality for most with haemophilia and HIV, the campaign for recompense was inspired.

84. Did THS play its hand well? Did THS naively stumble into Government and accept the crumbs offered? I do not recollect the detail of the agreement. It was, as Alan had said, "a start". It was not an end in itself and was never intended to be.

85. We continued to have good relations with MPs and Peers and would continue to draw upon their assistance and support. I recall Jonathan Aitken, as a back-bench MP, turning up at the THS office. Ron Davies MP was also very helpful. MPs would table questions on haemophilia, HIV or both. With regret, I do not recall the detail.

Section 6: Litigation

- **What role did the Society play in the HIV litigation? You may find it helpful to consider [RFLT0000004], [HSOC0026008], [HSOC0025977] and [RFLT0000093].**

- **In the Update newsletter dated October 1988, members of the Haemophilia Society were informed that "Please feel free to check your situation with the society – and it is easier to deal with those enquiries when they are in writing..." [DHSC0002041] Why did the Society invite these enquiries? Who dealt with enquiries from members? What were members told when they made such enquiries? Where did the information that was provided to them originate from?**

- **By fax dated 27 September 1989, David Watters informed lawyers for Claimants that a doctor had contacted him with "vital information" for the litigation [HSOC0023179]. Were you aware of this? Who was this doctor? What information did they have that was relevant to the litigation?**

- **In the January 1989 Update, it was noted that the Society had launched a campaign in 1989 to persuade the Government to settle the litigation claims ([ARMO0000704] and also [RFLT0000093]).**
  - **a. What were the goals and priorities of the campaign in relation to the litigation? How were the goals set? Who decided upon the goals, priorities and or strategy to achieve those goals?**
  - **b. To what extent (if any) was the campaign in relation to the litigation informed by the views of Haemophilia Society membership? Did these differ from the views of the Haemophilia Society Executive Committee, as you understood them?**
  - **c. To what extent (if any) did the Haemophilia Society achieve the goals set out in your answer to question 66a above, during your tenure?**

- **The January Update refers to the Society having "given advice about [seeking proper compensation through the legal system] since early 1987" and states that as a result between 500 and 600 cases were preparing to go to court [RFLT0000093]. Please explain:**
  - **a. What advice was given?**
  - **b. Who gave that advice?**
  - **c. On what basis was the Society qualified to give that advice?**
  - **d. Did the Society consult with lawyers before giving that advice? If so, who did they consult with, about what and when?**
  - **e. Please set out in detail what advice, if any, was received from lawyers.**

- **The January Update also refers to the Society holding a "list of those specialist lawyers who understand our cause" [RFLT0000093]. Please explain:**
  - **a. Who were these specialist lawyers?**
  - **b. How did they come to be on the Society's list?**
  - **c. Who decided which lawyers would be on the list and what criteria were applied?**
  - **d. Did the Society benefit in any way, whether financially or otherwise, from the lawyers being put on the list?**

- **As to the campaign in relation to the litigation, were the Society's goals communicated to the Government? Please set out an account of the Society's engagement with Government ministers, members of Parliament and Peers. Who did you meet, when and what was discussed? What response did you**

receive in the discussions? [HSOC0024307, HSOC0022185, HSOC0019591, HSOC0024277, HSOC0024261, HSOC0010409 and RFLT0000054 may provide some assistance].

- **What positions and assurances were made by the Government to the Society in relation to compensation during the relevant period? Who provided any such assurances? If this changed over time, please detail when and why.**

- **Were these assurances relied upon? If so, how?**

- **In a letter dated 4 January 1991, David Watters wrote to a solicitors' firm and stated that the Society had "worked consistently to guide people towards accepting what we feel certain counsel will regard as a fair and reasonable settlement" [HSOC0015341]. Did you share this view? How did the Society come to this view? Please explain the context of the exchange of letters.**

- **In the Bulletin in February 1991, it was noted that the Society's campaign for compensation had come to an end at the end of 1990 because the Government had acknowledged the need for an out-of-court settlement. The article said "The offer carried the condition that the great majority of those affected must accept the offer, or it would lapse" [HCDO0000279_009]. It goes on to say that the campaign "must be hailed as a success".**
    a. What was the Society's position in relation to the adequacy of the settlement?
    b. What did the Society advise its members about accepting the offer or not?
    c. The article states that although the campaign had ended, "the problem has not disappeared, and the tragedy is not forgotten". When you left the Society, what was anticipated that the Society would do going forwards? [HSOC0000002 may also assist].

86. Issues related to litigation were left to David and the trustees. I had no active involvement in those discussions and my recollection is hazy and therefore not reliable.

87. THS saw its role as supporting people with haemophilia and would therefore support people as best it could.

88. The initial advice THS had received stated that a group action could not succeed for all sorts of legal reasons, but THS was clear that individuals were entitled to pursue their own remedies. I recall a meeting where Alan and/or David said that in terms. The question had come from a haemophilia nurse on behalf of one of her patients.

89. THS wanted what was best for people with haemophilia. That would mean that cases should settle and people with haemophilia should not be forced through the courts to get their remedy.

90. I am not sure what more I can helpfully say, but if it would help for me to discuss this with you, I am happy to do so.

Section 7: Interaction with Trusts and Schemes

- **In the 1988 Annual Report [HCDO0000276_021] it is stated that during the first eight months of 1988, the administration of the Macfarlane Trust was carried out by the Society. Please explain why this was the case and what the Society did during that period.**

- **In a document headed "Some random and preliminary thoughts" dated 28 January 1988, David Watters wrote that "... when one opens a honey pot one expects flies!!"; you described those in debt as "classic mismanagement by mismanagers!"; that "members do not understand the difference between items campaigned for and those for which one has to settle" and that there was a "potential problem" that beneficiaries would "plot and scheme to take advantage of the Trust" [HSOC0013404]. He also set out different options for how the MacFarlane was established and whether it should be a charitable trust. Please explain:**
  a. Were you aware of David Watters' views as expressed in this document? b. If so, what did you understand him to mean in those views?
  c. Did those views impact any decisions taken by the Society? If so, how?
  d. Was expert assistance obtained in relation to the Society's view of whether the MacFarlane Trust should be set up as a charitable trust? If so, please explain who provided that advice and what it was.

- **Once the Macfarlane Trust was established, what role did the Haemophilia Society play in the operations of the Macfarlane Trust? What role did the Society play in making grants on behalf of the Macfarlane Trust?**

- **It is understood that initially there was no allocations policy in place. On what basis were the grants made by the Haemophilia Society during this time?**

- **In a letter dated 2 February 1988, David Watters referred to a survey of patients with HIV, ARC or AIDS which was "vital to help us with the allocation of the grant of £10m" [HSOC0004761]. Please explain to whom the survey was circulated, what the results of the survey were and how this informed the allocation of monies.**

- **Are you aware of any problems that were encountered in staff from the Society also performing a role with the Macfarlane Trust?**

- **At a meeting of the Macfarlane Trust held on 22nd August 1988, a proposal by the Allocations Committee for the new Allocations Policy was discussed [MACF0000017_006].**
  a. **Were you involved in formulating the new Allocations Policy? If so, please set out your role in detail.**
  b. **As a feature of the Allocations Policy, it is noted that Single Payment Grants, "will be available on the basis of need in its broadest sense, and not on the basis of income," and they are not just for, "helping to overcome a problem by paying a bill...but by providing things which offset stress". During your tenure at the Society, are you aware of whether these remained the guiding principles for allocations?**

- **At the same meeting as mentioned at paragraph 60, the attendees discussed the possibility of members of the Trust attending Regional Centres to meet medical and social workers and trust members to answer queries and put a face on the Trust [MACF0000017_006]. Were you aware of these meetings? How many such meetings took place? Where were they held? What was said and done at the meetings? [MACF0000004_107] Did you and/or other members of the Society also attend these meetings?**

- **During the meeting of the Haemophilia Society Policy Committee held on 9 November 1991 [HSOC0017239], concerns were raised regarding the relationship between the Macfarlane Trust and Haemophilia Society. It was discussed that the Society was receiving telephone calls from people asking that it intercede with the Trust on their behalf over grant requests. Could you please explain why there were concerns surrounding the relationship between the Haemophilia Society and Macfarlane Trust?**

- **To what extent, in your experience, was the Macfarlane Trust independent from the Government/ the Department of Health? How much oversight or involvement did the Department of Health (or any other government department) have in relation to the activities and workings of the Macfarlane Trust?**

- **Did you consider that the funding provided to the Macfarlane Trust by the Government was adequate? Please explain your answer.**

- **Did you, or any others within the Macfarlane Trust, raise any concerns or issues with the Department of Health about the funding, structure, organisation or running of the Macfarlane Trust, or about the involvement of the Department of Health, or about any other matter? If so please explain what concerns and issues were raised and what the response was received from the Department of Health.**

91. The trustees were clear that once the Macfarlane Trust was up and running, it was to be completely separate and distinct from THS. Other than in its initial stages there was therefore very little overlap. David maintained the links between THS and the Trust and when we met up, we had very cordial and friendly relations. I recall they had an excellent social worker, Tudor Williams.

92. The Macfarlane Trust impacted on my work mainly by refocussing it. I no longer dealt with welfare benefit issues or the everyday impact of HIV on the lives of people with haemophilia. This enabled me to focus more on HIV policy and its impact on people with haemophilia.

93. THS had to be up to speed on Macfarlane Trust issues because we'd be asked about them, but other than David's links, THS had no meaningful role within the organisation – at the beginning at least.

94. And, of course, it became complicated and some might draw all sorts of metaphors in relation to it, but I had no role in any of that. I also left THS in the summer of 1990. I have views, but I do not think these have any bearing on the Inquiry.

Section 8: Relationship with Pharmaceutical Companies

8.1 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.**

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

- **What monies were provided to BPL over your tenure? What benefit did the Society derive from the relationship with BPL? Were research funds provided to any of the pharmaceutical companies?**

- **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.**

- **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?**

- **Please explain any differences between the relationship of the Society 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?**

- **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?**

- **A number of the Haemophilia Society Bulletins record which pharmaceutical company funded the production of the Bulletin. Was that record a requirement of their funding? What was agreed in this regard? How was this agreed?**

- **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.**

- **To what extent did pharmaceutical companies rely (if at all) on the Haemophilia Society to improve their public image through its activities and functions? If so, please provide details, specifying the pharmaceutical companies as well as the way in which the Haemophilia Society were expected to improve their public image.**

- **In the General Secretary's Report in November 1989, David Waters stated that, "Armour are very much about the business of improving their public image in the UK prior to obtaining a full product licence for MONOCLATE. I have spent more than a little time with them discussing issues - and extracting money - However, this is time consuming and reminds me one of the 'there's no such thing as a free lunch' maxim!" [HSOC0024307, page 1]. Were you aware of these types of meetings? Did you attend any such meetings? What were you told about them? What was your understanding of why meetings took place with**

pharmaceutical companies? What was your understanding of the benefit to the pharmaceutical companies in meeting with the Society?

- **Please comment on the article, "Alpha Therapeutics UK Ltd - A Decade of Service to Haemophilia", published in Update No.3 June 1989 [HCDO0000276_018, page 5]. Who wrote this article? To what extent did Alpha rely (if at all) on this publication disseminated by the Haemophilia Society to promote their products or their public image?**

- **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.**

- **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.**

95. As I have mentioned, my role in fundraising was limited. I was involved in outward facing fundraising which was more concerned with comms and PR than raising money. For example, I worked with CRUSAID on organising a Private View of the Frans Hal exhibition at the Royal Academy with the Duchess of Kent (THS's Patron). This event raised money, but it was as concerned with messaging. I also organised a prisoners' art exhibition in a trendy Chelsea art gallery.

96. The pharmaceutical companies were David's domain. I would meet with them along with him and discuss our work, but he led on all of these relationships.

97. David gave effect to THS's policy in relation to blood products. The Society wanted top quality products that were as safe and effective as they could be. For multiple reasons there was what I would describe as a romantic aspiration for self-sufficiency, but there was also a pragmatic realism. If the private sector was ahead of the game in relation to quality and safety, THS would support access to those products.

98. The trustees were the true experts. Pharmaceutical companies supported the work of THS but in a very understated way. David would not chase their funding, but he would

expect it. He recognised that the pharmaceutical companies were an essential part of enhancing the lives of people with haemophilia, but he kept them at arm's length.

99. With regret I do not recall the detail of THS's relationship with BPL, but they were a major player for THS and David treated them accordingly.

100. In relation to the pharmaceutical companies, David reverted to type. At the end of the day, he's a dour Scot and was uninterested in the baubles of sponsorship. Pharmaceutical funding was necessary. That was all. It gave them no fear or favour within the Society. I recall dinners and events that they paid for, but without any concept of reciprocity. I have a vague memory that they paid for me to go to the WFH conference in Madrid, but that gave them no influence.

101. These were exciting times for blood products. Was it a new dawn? We were all interested in the recent developments. It was the science that engaged us and that we discussed, not the corporations.

102. Again, I am not sure how much more I can add to this big picture of THS's relations with the manufacturers of blood products. I can't recall the details required to answer the questions posed by the Inquiry in any meaningful way.

8.2 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.**

- **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 left?**

- **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. [BPLL0002037] may assist you.

- **What was the purpose of pharmaceutical representatives speaking at Regional Group meetings of the Haemophilia Society?**

103. See above

Section 9: Other Issues

- **To the best of your knowledge, at any point, did Haemophilia Society staff and committee-members purposefully or unintentionally destroy documents relevant to the Terms of Reference of the Infected Blood Inquiry?**

- **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.**

104. I think it is best to describe the leadership of THS when I worked there as rooted in a Christian tradition in a very practical way. All the key players were motivated by their faith. That faith would have precluded them destroying documents and papers. Both David and Alan believed in transparency and accountability. They lived by the highest standards of good practice. This was the same for Andy, Caroline and Ken, the trustees I worked most closely with. It is also inconceivable that Linda would have destroyed records or information.

105. The people connected with THS were caught up in a catastrophe. They did their best in the circumstances and all of them would have expected to be held to account for the decisions that they took and would not shy away from that.

106. With hindsight, would I have spent my three years at THS differently? Ideally, yes. I would have been better and done more, but we constantly fought fires. What I do not question, is the quality of THS's leadership and their decision-making processes.

Statement of Truth

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

GRO-C

Signed:

Dated: 25 February 2021