Witness Name: Keith Colthorpe
Statement No: **WITN 4430001**
Exhibits:
Dated: 14th May 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KEITH COLTHORPE

I, Keith Gordon Colthorpe, of GRO-C Essex will say as follows: -

1. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 November 2020 based on my own knowledge and experience.

2. I was a member of the Haemophilia Society from late 1953 (having been signed up as a child) and was elected as a member of the Executive Committee (subsequently the Board of Trustees on incorporation of the Society) from 1984 to approximately 2002.

3. I have adopted the numbering of the questions from the Inquiry in the response below. I do not recall precisely when the Haemophilia Society became a company limited by guarantee, so when I refer to the 'Executive Committee' or 'Board of Trustees' in my statement below, that should be taken to refer to either the Executive Committee or the Board of Trustees, whichever was the relevant classification at the time. I have referred to the Haemophilia Society as 'the Society' throughout my statement.

Section 1: Introduction

Question 1: Please set out your name, address, date of birth and professional qualifications

4. As set out above, my name is Keith Gordon Colthorpe of GRO-C GRO-C Essex GRO-C I was born on GRO-C 1952.

5. I am a qualified Fire Service Manager and Instructor. I have no other formal professional qualifications.

Question 2: 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.

6. I worked:

a. From December 1969 – November 1970 as an office junior in Tilbury Docks for a company called T Wallis, Smith Coggins;

b. From 1970 to 15 May 1973 as a TV Engineer for The Grays Electrical Company ; and

c. From 16 May 1973 to 5 September 1974, as Freelance Contract TV Engineer.

7. I do not have exact job descriptions for those roles.

8. On 16th September 1974 I joined the Essex County Fire and Rescue Service as a Control Operator. This role involved reception of emergency calls, selection and mobilisation of appropriate fire appliances (vehicles) and liaising with other emergency services. I rose through the ranks rapidly and was promoted to Leading Fire Control Operator within 4 years. I was in that role until approximately 1980 when I was again promoted to Senior Fire Control Operator. I remained in that role for 29 years.

9. I retired in the rank of Senior Fire Control Officer on 27th March 2012.

10. As referred to above, I was a member of the Haemophilia Society ('the Society') since I was a child, in 1953. I became more active as a member when a local group in South Essex formed in the early to mid-eighties. In 1984 I was elected as a member of the Executive Committee, having put myself forward for that position. The members of the Executive Committee, including myself, became Trustees when the Society became a company limited by guarantee. I do not recall the exact end date of my tenure. My last term as a Trustee began in or around 2001. I believe Trustee/ Executive Committee terms were for three years. However, I recall that I did not complete my last term and instead decided to step down early. **HSOC29689** shows I was still a Trustee for the following 12 months so I think that I must have left in or around 2003.

11. In my role as member of the Executive Committee/ Board of Trustees I was the link Trustee for the Northern Ireland Group of the Society. This involved visiting the group, supporting them, communicating ideas and listening to any of their concerns. This brought Northern Ireland more 'into the fold' of the Society. I also started the Christmas card sales (and some associated promotional gifts which were dropped from sale at a later date) for the Society which promoted the Society and raised funds. I also had a role to maintain and check on the accommodation and chalets that the Society maintained as part of the services provided to members, which were used as low cost (or sometimes free) holiday accommodation for members. I was not involved personally in communications with or lobbying of the Government etc. There were other Executives who took on this role, such as Simon Taylor, and they were very good at that.

12. Fortunately, the shift pattern for my roles with the Fire Service allowed me to attend Haemophilia Society meetings fairly regularly. When dates clashed with shifts, as long as there was an equivalent rank available, I would take annual leave days to attend or on some occasions swap shifts with an officer of equivalent rank on another watch.

Question 3: Please set out your membership, past or present, of any committees, groups, associations, societies or working parties (not including those within the Haemophilia Society) relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

13. I have not served on any other committees, groups, associations or working parties relevant to the Inquiry's terms of reference, other than those I have mentioned above and below within the Society.

Section 2: Previous Evidence

Question 4: 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.

14. I have not provided evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to HIV, Hepatitis B or C, CJD in blood or other products.

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

Question 5: 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.

15. I joined the Society in late 1953. I was a child at the time, and, as a result, I was not aware of the objectives and functions of the Society at that point. In my early teen years I became aware that the Society provided peer support. It would not have been until I joined the Executive Committee in or around 1984 that I understood the objectives and functions of the Society in any detail.

16. Given the passage of time, I do not have a clear recollection of what the objectives and functions of the Society would have been. I believe when I joined the Executive Committee, these included:

    a. Providing peer support;

    b. Where possible, helping fund items of equipment beneficial to members at Centres not provided by the NHS, for example treatment chairs, TV and children's amusements in waiting areas;

c. Encouraging the formation of local groups where members could meet and share experiences and knowledge; and

d. Making grants for domestic equipment and telephones to members in need;

17. I also believe the Society provided some funding for research. However, this would only have been to assist Haematologists or other clinical specialist in the area of haemophilia doing some form of small-scale research, or to assist a research project getting off the ground. Latterly this became too expensive for the Society's funds and so such funding fell away. I do not recall when that happened. I do not recall if the other objectives and functions changed over time.

Question 6: Please describe how the organisation was structured, including the governance 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.

18. I do not recall the structure of the Society when I joined in late 1953, nor when I became an Executive Committee member in 1984. I would need to review a copy of the Society's Constitution at the time and any subsequent iterations. It is likely to have comprised of a Committee with a Chairman, Vice Chairman, Secretary, Treasurer and a number of Committee members, which is the standard structure of such organisations.

19. The key structural change over the period I was a member of the Haemophilia Society, was the Society becoming a Company limited by guarantee. At this point, the Constitution was dropped and 'The Memoranda of Articles of Association' (as I believe it was called) superseded the Constitution.

Question 7: Please describe the relationship between the Board of Trustees, Council, Executive Committee and the day-to-day management of the Society.

20. I don't recall specifically how the relationship between the Board of Trustees, Council, Executive Committee and the day-to-day management of the Society was structured. However, my recollection is that the Council was comprised of representatives from local groups that met several times a year with Executive Committee members to discuss group needs and for groups to pass on successes and new ideas to others. The day-to-day management of the Society was the responsibility of the Chief Executive Officer, following the policy decisions of the, now, Board of Trustees.

21. The role of the Board of Trustees / Executive Committee was to make decisions on policies, procedures and publications. Actions based on those decisions were then given to the staff members, who then actioned that. Society staff members were paid members who worked there 5 days a week. Trustees were volunteers and only met approximately once per month to make policy decisions. The staff members could also make proposals to the Trustees about how and why the Society should (or shouldn't)

take certain actions (for example if funds were not available). Such proposals could be made by letter or a paper tabled to be discussed at the executive meeting. David Watters also always attended the Executive Committee/Trustee meetings and so was able to both communicate staff proposals at meetings and refer back decisions from the Executive Committee to staff members. To the best of my recollection, the relationship between staff and the Executive Committee was a good one.

Questions 8: The Inquiry is aware that you were an Executive Committee-Member of the Society from 1984 to 1991, 1993 to 1996, and 1998 to 1999, and you were elected Vice Chair in 2001. Please confirm and explain what your role and responsibilities were in relation to each tenure and how your role and responsibilities changed over time (if at all).

22. I don't recall exactly when I was a member of the Executive Committee as it was then known, latterly to become the Board of Trustees. The information and documentation supplied by the Inquiry appears to show it was 1984 to 1991, 1993 to 1996 and 1998 to 1999. My role required me to take an active role in discussions, and decision making, along with giving input from my personal perspective, as a Severe Haemophiliac. I don't remember how or if my role or responsibilities changed over my period of being a Trustee.

23. I seem to have a spurious date of '2001' with no end date, when I was supposed to have been Vice Chair. I have no recollection of being Vice Chairman. From the minutes provided I have read at no stage am I listed as being Vice Chairman. As far as I was aware, I never held office, other than being a member of this committee. It is possible that I deputised as Vice Chairman in a meeting, but have no recollection of doing so.

24. As mentioned above, my last term as a Trustee began in or around 2001. I believe Trustee/ Executive Committee terms were for three years. However, I recall that I did not complete my last term and instead decided to step down early. **HSOC29689** shows I was still a Trustee for the following 12 months so I think that I must have left in or around 2003.

Question 9: Please list all the different Haemophilia Society sub-committees, "task groups" and/or advisory bodies that you were involved in and describe the purpose, functions and responsibilities of each committee, "task group" and/or advisory body. Please include a description of the Policy Committee, Services Committee, the Finance Committee, the Blood Products Task Group, the Health Sub-Committee and the Information and Communication Sub-Committee and the nature and period of your involvement. [You may be assisted by ***HSOC0023353*** *and* ***HSOC0015303****].*

25. I have reviewed documents **HSOC0023353** and **HSOC0015303** as well as documents **HSOC0029689005 HSOC0015303** and **HSOC0029689045**. Given the passage of time and the length of my involvement with the Society, I don't specifically recall all the

Haemophilia Society sub-committees, task groups or advisory bodies I was involved with, nor the nature and period of my involvement.

26. However, based on the minutes provided, it appears I was on the 'Services Committee' and the 'Policy Committee', it also shows I was on what was called the 'Resources Sub Committee'. I'm not sure how I became involved with the Resources Sub-committee, as I am, and always have been hopeless with anything to do with accounts. It may have been due to my involvement with the Christmas card sales. I was also involved in the Blood Products Task Group and Blood Products Sub-Committee. **HSOC29689-045** refers to my being on the Info/Communications Sub Committee, although I really don't remember this at all.

27. The Resources Committee's role, I believe, would have been to keep track of where the Society's finances and to ensure appropriate information was available to the membership.

28. The Policy committee members were responsible for considering whether new policies needed to be prepared, if old policies required replacement, and for reviewing or drafting those policies. Any proposals for new policy or replacement/amendment to policy would be put before the Executive Committee, as would any drafts. Decisions were made by the Committee and implemented by consensus.

29. The Services Committee prepared and provided information to members, took the lead on the publication (the Bulletin) and may have had meetings about specific subjects which we thought information should be published about.

30. The Blood Products Task Group and Sub-Committee monitored advances in treatments for blood products, and would review any new papers or information presented to the Society.

31. I do not recall being on the Finance Committee, the Health Sub-Committee or the Information and Communication Sub-Committee (though I can see I was listed as being on the Information and Communication Sub-committee in document **HSOC0029689-045**). I really don't remember the function or responsibilities of those committees. However, the minutes of those meetings do give some indication of what they did, as does **HSOC0015303**. I also seem to remember that people did not always serve on these committees for the full period of election as a Trustee but moved from time to time.

Question 10: To the best of your knowledge, please list all the committees, "task groups" and/or advisory bodies that the Haemophilia Society's Executive Committee, Trustees and staff relied on for medical advice and opinions on the safety of blood products and/or the risks of transmission of HIV and hepatitis. Please include, where possible, details on the extent to which (if any) they were staffed by members of the Haemophilia Society, external advisors, pharmaceutical representatives and/or clinicians.

32. To my knowledge, the only bodies the Executive committee and staff would have relied on for advice and opinions on the safety of blood products would have been relevant scientists in the field (although I don't remember who they were) and probably from eminent Haematologists at that time. Arthur Bloom, whom I think was a Haemophilia Centre Director and Peter Jones, a Haemophilia Centre Director in (I think) Newcastle, are the only names I remember who may have given advice. Depending on skills on the Medical Advisory Panel at any given time, I assume we approached them as well. I don't remember, but I do not think advice would have been sought any advice from pharmaceutical companies as they had a vested interest in the use of their products.

33. As for the staffing of these groups, I don't remember. However, Haemophilia Society staff with particular knowledge or functions may have been involved. As mentioned above, I don't think pharmaceutical representatives would have been part of those groups. Probably, on occasion, clinicians may have been involved for their expertise. I provide more information in my response to Question 11 and the questions that follow.

Sub-section 3.1 The Medical Advisory Panel

Question 11: 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.

34. Given the passage of time, I do not recall in great detail the purpose, function and responsibilities of the Medical Advisory Panel and if (or how) this changed over time.

35. To the best of my recollection, the Medical Advisory Panel was there to give the Executive Committee / Board of Trustees advice on medical subjects about which the Executive Committee would have had little or no knowledge, being anything, which required medical specialist knowledge. They also may have helped the Executive Committee understand in 'lay terms' any medical information that may have been too technical for us to understand.

Question 12: 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?

36. The Medical Advisory Panel gave advice to the Executive Committee (and the sub-committees) on medical issues. The Executive Committee would have relied on the members of the Medical Advisory Panel for that expertise. For example, if there was a paper or medical journal published on safety of blood products, the Executive Committee would probably have referred to the Medical Advisory Panel for their views.

37. The Medical Advisory Panel would have been the main source of information on the safety of blood products and/or the risks of infection from hepatitis and HIV. It is unlikely that the Executive Committee would have referred questions to anyone else, at least until there became HIV specialists. Even then, it is likely those specialists would have been added to the Panel.

38. However, if there was new information on a topic outside the skill set of the Medical Advisory Panel, the Society was able to seek views from other experts with whom they had a relationship. I cannot recall any of those experts specifically. I do recall a hepatologist who was consulted regarding Hepatitis C questions at one point. However, I cannot recall who he was and whether he became a member of the Medical Advisory Panel.

*Question 13: 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.*

39. I cannot remember how the members of the Medical Advisory Panel were selected, what the basis for selection was, or whether there was any change in the process over time. I was not involved in that process. I do not know how the membership itself changed over time. I think this was likely due to individual choices, rather than anyone being asked to leave.

40. Having reviewed **PRSE0000956** I can see who the members of that panel were during the 1980s and that the composition of the panel changed over that period. I do recognise some of the names as being eminent Haematologists: Professor A L Bloom; Dr B. Colvin; Professor R.M Hardisty; Dr P Jones; Dr E.E Mayne; Dr C R Rizza; Dr E.G. D Tuddenham; and Dr P Kernoff, are names I recognise. However, I ever only knew Dr Tuddenham, Dr Kernoff, Dr Jones, Dr Colvin and had spoken to, Dr's Kernoff and Tuddenham being my Centre Directors. Some others I don't recognise and may have had expertise in areas of HIV or Hepatitis C.

*Question 14: Please confirm that the Medical Advisory Panel did not meet in person until 1988 [**HSOC0010470**]*

41. I can't confirm that the Medical Advisory Panel did not meet in person until 1988, as I personally have no knowledge of when they first met. However, it would appear from **HSOC0010470** that members of this panel did not meet until 1991 when this document sets out the terms of reference and functions of the panel.

Processes prior to 1988

Question 14(a): How was advice sought from the Medical Advisory Panel?

42. From document **HSOC0010470**, it appears the Medical Advisory Panel members were expected to inform the Executive Committee of any developments (such as any new treatments, safer treatments, advances in medicine relevant to haemophilia sufferers etc.). I think that where the Executive Committee needed advice on a particular subject, the appropriate member/s would have been contacted for that advice, or the panel as a whole. To the best of my recollection, I never sought advice from the Medical Advisory Panel directly.

Questions 14(b): Who decided when and about what matters advice would be sought?

43. I believe the Executive Committee decided what matters advice should have been sought from the Medical Advisory Panel, as and when required. It may also have been in response to questions asked of the Society to which the Executive Committee or staff did not possess the knowledge to answer.

Questions 14(c): Was advice sought from all members of the Medical Advisory Panel or only selection of them? If a selection, how was that selection determined?

44. I believe advice was sought from the Medical Advisory Panel either on an individual basis, or from the whole panel as required. I don't honestly remember.

Questions 14(d): How were matters discussed by members of the Medical Advisory Panel?

45. I don't know how matters were discussed by the Medical Advisory Panel as I never attended any meetings or discussions. The Medical Advisory Panel met separately to the Executive Committee. The Medical Advisory Panel would provide information to a member of the Committee (or appropriate member of staff), who would then present this at the Executive Committee meeting.

Questions 14(e): Did some members of the Medical Advisory Panel have more influence than other members, and if so, who carried more influence than others?

46. I have no idea if any member of the Medical Advisory Panel had any more influence than another. As stated in relation to question 14(d) above, the Medical Advisory Panel met separately to the Executive Committee so I did not witness or was privy to their interactions. I do not recall having much, if any, interaction with members of the Medical Advisory Panel, other than perhaps informally at a conference.

Questions 14(f): How was advice communicated from the Medical Advisory Panel to the Society?

47. I don't know how advice was communicated from the Medical Advisory Panel to the Society. As mentioned above, information from the Medical Advisory Panel was presented to the Executive Committee by a member of the Committee. I do not recall being in direct contact with members of the Medical Advisory Panel and did not present their findings/information so cannot say more on how that was communicated.

Questions 14(g): How was the Panel's advice recorded once it was received by the Society?

48. I don't know how the Medical Advisory Panels' advice was recorded once it was received. I assume it was kept on file.

Questions 14(h): 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?

49. Unfortunately given the passage of time, I am unable to recall the specifics of what issues we might have requested advice on from the Medical Advisory Panel. I am therefore unable to advise if any of those may have been relevant to the Inquiry, or what advice they may have given. It is possible that we may have requested advice or information about transmission of the viruses and the best treatments available, I don't remember.

Question 15. Medical Advisory Panel processes prior to 1988

Question 15(a): How was advice sought from the Medical Advisory Panel?

50. I don't remember how advice was sought from the Medical Advisory Panel, prior to 1988. I would have thought that either individuals or the Panel as a whole were either written to, or emailed seeking the advice.

Question 15(b): Who decided when advice would be sought?

51. I don't remember who decided when advice would be sought. Again, I would have thought it would have been the Executive Committee.

Question 15(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?

52. I don't remember if advice was sought from one or all individuals of the Medical Advisory Panel. If a selection of members were asked for advice, I can imagine that would have been because of their skills / knowledge of the subject.

Question 15(d): How were matters discussed by members of the Medical Advisory Panel?

53. I was not on the Medical Advisory Panel and did not attend their meeting, and so don't know how matters were discussed by members of the Medical Advisory Panel.

Question 15(e): Did some members of the Medical Advisory Panel have more influence than other members, and if so, who carried more influence than others?

54. I don't know if any individual members of the Medical Advisory Panel carried any greater influence than others as I never meet with them for the same reasons as set out to my response to question 14(e) above.

Question 15(f): Were matters discussed at times other than the in-person meetings of the Panel?

55. I don't know if matters were discussed at times other than in meetings of the Panel, as I was not a member of the Panel.

Question 15(g): How was advice communicated from the Medical Advisory Panel to the Society?

56. I do not know how advice was communicated from the Medical Advisory Panel to the Society for the same reasons as set out to my response to question 14(f) above.

Question 15(h): How was the Panel's advice recorded once it was received by the Society?

57. I don't know how the Medical Advisory Panel advice was recorded once it reached the Society. I think it is likely that it was copied and circulated to the relevant Group, Sub-committee, task group, or Executive Committee as a whole in a meeting. I would guess a copy would have also been held on file.

Question 15(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?

58. I don't remember what advice would have been sought of the Medical Advisory Panel which may have been relevant to the Inquiry's Terms of Reference, or what advice was provided.

Question 16. As far you can recall, please describe:

Question 16(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;

59. I don't remember the extent to which the Haemophilia Society relied on its own judgment when deciding whether or not to formulate policy on the basis of the Medical Advisory's Panel. However, it is likely that the Haemophilia Society took some of the information from the Medical Advisory Panel to assist in formulating policy.

Question 16(b): All examples, relevant to the Inquiry's Terms of Reference, of when the Society did not follow the Medical Advisory Panel's advice;

60. I don't remember and so I can't give examples of when the Society did not follow the Medical Advisory Panel's advice.

Question 16(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;

61. I have no examples of when the Medical Advisory Panel disagreed with the advice of the Chair of the Panel, having never been in meetings with them, and not being told at any time they disagreed.

Question 16(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.

62. I don't know of any examples of when the Haemophilia Society did not follow the advice of the Chair of the Medical Advisory Panel.

*Question 17. 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**]:*

63. I have reviewed document **HSOC0010277**. However, I am not aware, or cannot recall how the review into the workings of the Medical Advisory Panel came about. Therefore, my responses to your questions 17(a) – (c) are somewhat limited. I have responded specifically to those questions below:

Question 17(a): The representatives of the Society and the members of the Medical Advisory Panel felt disappointed with the substantive outcomes of their meetings

64. I don't know, or cannot remember who alerted us to the disappointment felt by the Medical Advisory Panel.

Question 17(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";

65. I have no knowledge of this. However, I can understand how Medical Advisory Panel members may have had a sense of loyalty to their Centre if they were a Centre Director. That may have put them in an awkward position in making independent decisions, if their Centre was not providing the same products or services that the Society was recommending. As I said, I did not have much interaction with the Medical Advisory Panel so did not have any discussions about this with the Medical Advisory Panel members, to the best of my recollection, myself.

Question 17(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.

66. I have no recollection of the concern being raised to me 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. I am therefore unable to provide a view.

*Question 18. 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**].*

67. I am unable to say how the purpose, function and responsibilities of the Medical Advisory Panel changed after the review. Having reviewed **HSOC0010470**, I can see that clear Terms of Reference were prepared both for members of the Medical Advisory Panel and members of the Executive Committee to work to. I cannot say whether these Terms of Reference came into being or were implemented.

*Question 19.In the Board of Trustees Meeting held on 25 March 1999, the Chief Executive noted that several members of the Medical Advisory panel were also members of the Society's own "Health Sub-Committee" [**HSOC0029689_025**]. To the best of your knowledge, which members of the Medical Advisory Panel were also members of the Health Sub-Committee? What was their role as members of the Health Sub-Committee?*

68. I have read **HSOC0029689_025**. I don't know who the members of the Medical Advisory Panel were that were also on the Health Sub-committee, nor what their role as members of the Health Sub-Committee would have been. Dr Mark Winter is in my mind as attending some of our meetings, although which ones I can't remember. However, if he was a member of the Medical Advisory Panel at the same time, I have no idea.

3.2 Blood Products Task Group

*Question 20. Please describe the purpose, function and responsibilities of the Blood Products Task Group and the extent of your involvement with the group. To the best of your knowledge, please detail whether it was a successor to the "Blood Products Sub-Committee" set up in the Haemophilia Society in the 1980s. [You may be assisted by **HSOC0029476_039** and **HSOC0029689_005**].*

69. I have reviewed documents **HSOC0029476_039** and **HSOC00299689_005**. I can see that I was a member of the Blood Product Task Group. However, I don't recall the purpose, function and responsibilities of the Blood Product Task Group in any more detail than described above, in my response to question 9. Given the passage of time, I find it difficult to differentiate between the responsibilities and the tasks undertaken by the Blood Product Task Group vs Blood Product Sub-Committee.

70. I don't remember if the Task Group was a successor to the Blood Products Sub-Committee. In my experience a 'task group' is more likely to be set up to complete a specific task/action (so more limited in its scope and purpose), whereas a 'sub-

committee' is a more long-standing group. I cannot recall if that was the case here, nor the specific task the Blood Product Task Group would have been set up to address, if that was in fact the case.

Question 21. Please set out your involvement with the Blood Products Sub-Committee. In particular, please respond to the following questions to the best of your knowledge:

Question 21(a): What was the role and function of the Blood Products Sub-Committee? When and why was it formed?

71. One of the functions of the Blood Products Sub-committee was looking at the inactivation of the HIV virus by Heat Treating. I do vaguely remember that the Blood Products Sub-Committee looked at developments in the inactivation of the virus, which may have included Pharmaceutical Company products, including the Blood Products Laboratory. I am otherwise unable to recall the role and functions of the Sub-Committee. I cannot remember when it was formed although **HSOC0029476_039** shows it being in existence as far back as August 1984.

Question 21(b): Over what period of time was the Blood Products Sub-Committee in existence? When and why did it stop meeting?

72. I cannot advise with any specificity over what period of time the Blood Products Sub-Committee was in existence. **HSOC0029476_039** shows it was in existence from August 1984 and at least until June 1994, as indicated in **HSOC0029689**. I cannot recall why the Sub-Committee stopped meeting. It may have come about with the introduction of Heat-Treated Products and Recombinant factor VIII products as there would no longer have been any need for a group dedicated to safe blood products, once those products were implemented.

Question 21(c): How often did the Blood Products Sub-Committee meet?

73. I am not sure how often the Blood Products Sub-Committee met. I believe other sub-committees met every 2 to 3 months.

Question 21(d): Who were the members of the Blood Products Sub-Committee? How were members selected to join the Sub-Committee? What criteria, if any, were used?

74. The members I can identify over the period August 1984 to at least June 1994, from documents supplied, are Ken Milne, Dr David Evans **GRO-D** myself Keith Colthorpe and Gordon Clarke. Dr Evans was probably asked to Chair the Group as I think he was a retired Centre Director. All other members were Haemophiliacs with an interest in the effectiveness and development of Blood Products and their safety. Over that period of time, I have no doubt others came and went, but I don't recall who they might have been. To the best of my recollection, I don't think any specific criteria was set down regarding membership.

Question 21(e): What sources did the Blood Products Sub-Committee rely on to produce its discussions and reports?

75. I don't remember the specific sources that the Blood Products Sub-Committee relied on to produce its discussions and reports. However, I think it would have been information from Pharmaceutical Companies or the Blood Products Laboratory. Although I am sure we would not have accepted such information unless it had been verified, probably by the Medical Advisory Panel. Information on developments in treatments may also have found their way to the Sub-committee from the Medical Advisory Panel.

*Question 21(f): Please explain the relationship between the Medical Advisory Panel and the Blood Products Sub-Committee. To what extent were comments sought from the Medical Advisory Panel before the reports and/or discussion documents from the Sub-Committee were produced and/or disseminated? [**HSOC0029476_033**, page 2; **HSOC0029476_042**, page 4]. To what extent (if any) were any other medical professionals consulted in the preparation of reports from the Blood Products Sub-Committee?*

76. I have reviewed both **HSOC0029476_042** and **HSOC0029476_033**. I don't remember the relationship between the Medical Advisory Panel and the Blood Products Sub Committee. Document **HSOC0029476_033** records a meeting that took place before I was elected onto the Executive Committee, which would have been in the mid to latter part of 1984 at the AGM. I therefore am unable to comment on this specific example of seeking input on a report from the Medical Advisory Panel.

77. The meeting recorded in **HSOC0029476_042**, must have been one of my first meetings. I probably had not joined any Groups or Sub-Committees at that very early stage. I am quite taken aback by the comment *"no evidence to show that UK products were any safer than imported ones"*. Although I think that, at that time, probably very little was known about the blood borne transmission and the risks of imported blood (which I discuss in more detail in response to questions 25 and 62 below).

78. I do not know who would have been consulted in the preparation of reports from the Blood Products Sub-Committee at the time. Although I cannot comment on the process for the specific reports/papers referred to in **HSOC0029476_042** and **HSOC0029476_033**, in my experience any medical questions would be referred to the Medical Advisory Panel in the first instance, likely by the Chair of the Executive Committee, unless it involved a particular expertise which the Medical Advisory Panel did not have (for example physiotherapy). I do not recall seeking any such consultation myself directly, that would have been others in the Sub-Committee. **PRSE0000956** shows who were members of the Medical Advisory Panel over the 1980s. I do now recognise some of the names as being eminent Haematologists, some I don't recognise and may have had expertise in areas of HIV or Hepatitis C.

Question 21(g): To what extent, if at all, did the Haemophilia Society rely on findings or conclusions from the Blood Products Sub-Committee to form its policies?

79. I don't know if the Haemophilia Society relied on the findings of conclusions from the Blood Products Sub-committee, but any findings would have ultimately been discussed in the Executive Committee and a decisions made by the Executive Committee based on the information shared.

Question 21(h):): To what extent did the Haemophilia Society verify the accuracy of reports and discussion documents produced by the Blood Products Sub-Committee? If so, please provide details.

80. I am unable to recall to what extent the Haemophilia Society verified the accuracy of reports and discussion documents produced by the Blood Products Sub-Committee.

81. I would have thought that the verification of accuracy would have been in the remit of the Blood Products Sub-committee, but cannot remember. If there were any doubts about the accuracy of information, the Sub-Committee likely sought input from the Medical Advisory Panel and/or would present those concerns to the Executive Committee for consideration. However, I cannot recall any specific examples of this occurring.

Question 21(i) How were the reports prepared by the Blood Products Sub-Committee disseminated (if at all)? To whom were they sent? Were the reports provided to the Government or individuals in public office? If so, please provide details.

82. To the best of my recollection, the Groups and Sub-committees prepared reports which were sent to or given to members of the Executive Committee. I don't recall if such reports were ever provided to the Government or individuals in public office, although it is possible.

*Question 21(j): What was the nature of the relationship between the Blood Products Sub-Committee and Elstree Blood Products Laboratory ("BPL")? What role did the Blood Products Sub-Committee play in BPL's policy decision making, if any? How (if at all) did this relationship change over the course of your tenure? [**HSOC0019504**, page 6]*

83. From the little I can remember there was a fairly open relationship between the Blood Products Sub-Committee and the Elstree Blood Products Laboratory. To the best of my recollection, I believe they provided us with information and kept us up to date on developments in the processes used and safety of blood products. I recall being invited to attend the laboratory to see, first hand, the quarantine processes that were used on blood products. It would appear from **HSOC0019504** that communication was taking place between the Haemophilia Society and Blood Products Laboratory.

84. I was aware that the Blood Products Laboratory had production problems, and I personally had to use imported Factor 8 because of this, but I am fairly certain that UK never achieved Self Sufficiency.

85. I think we always had a fairly open relationship with BPL and don't recall it changing at all during my tenure. As far as I am aware the Blood Products Sub-Committee played no part in BPL's Policy decision making.

*Question 21(k): A review of the Society's policies was apparently undertaken by the Sub-Committee and set out in a report dated 9 January 1984 [**PRSE0000851**]. This report was, "conducted against a background of medical advice having been obtained from an appropriately qualified doctor … the source material listed as justifying the view expressed in that report come predominantly from articles written by members of the medical profession". Please address the following matters:*

86. I have reviewed document **PRSE0000851**. I was no longer a Trustee for the Society at the time **PRSE0000851** was written, November 2011. I had not been elected to the Executive Committee (nor was I on any Sub-Committee) at the time of the *review of the Society's policies and the report into that dated 9th January 1984*". I therefore don't remember this review. A review of **PRSE0000851** also suggests the review in the early 1990's was possibly carried out / co-ordinated by David Watters. I do not recall having any involvement in that process. I am therefore unable to answer with any specificity the questions posed by the Inquiry at Question 21(k)(i) – (vi). I have, however, provided specific responses below:

Question 21(K)i Which medical professionals provided the "background of medical advice"?

87. I have no idea which medical professionals provided the *"background of medical advice"*.

Question 21(K)ii How was this medical advice sought?

88. I don't know how medical advice was sought.

Question 21(K)iii How was this medical advice recorded?

89. I don't know how this medical advice was recorded.

Question 21(K)iv Who decided which articles would be considered in determining the view of the Sub-Committee?

90. I don't know who decided which articles would be considered in determining the view of the Sub-Committee as I was not on the Executive Committee or any of the Sub-Committees at the time.

Question 21(K)v How were the views of different articles weighed by the Sub-Committee? In particular, which members of the Sub-Committee had medical experience to undertake that weighing exercise?

91. I don't know how the views of different articles were weighted by the Sub-Committee. I don't know which members of the Sub-Committee had medical experience to undertaken that weighing exercise.

Question 21(K)vi It is said that the views came "predominantly" from articles. How else were views formed? On what material were such views based?

92. I don't know what articles are being referred to, however, it is likely they were written by Doctors and Scientists.

*Question 22. The Blood Products Sub-Committee reported on new commercial products, such as Monoclate from Armour Pharmaceuticals [**HSOC0019923_020**, page 2].*

Question 22(i) What information did the Sub-Committee receive about these products from pharmaceutical representatives in advance of their release? :

93. I have reviewed **HSOC0019923_020**. I don't know or don't recall what information the Sub-committee received about new commercial products from pharmaceutical representatives in advance of their release. **HSOC0019923_020** refers to Monoclate being 'mentioned' by Armour Pharmaceuticals, but the document does not give any further information and I am unable to expand on this.

Question 22(ii) Did the Blood Products Sub-Committee investigate the safety of commercial blood products? If so, where was the information concerning the safety of these products sourced?:

94. I don't recall the Blood Products Sub-Committee investigating the safety of commercial blood products. We would not have had the knowledge or expertise to do that. I would assume any information on the safety would have come via the Medical Advisory Panel or, if external information was received, it would have been sent to the Medical Advisory Panel for a clinical view/ verification.

Question 22(iii) Was the Medical Advisory Panel involved in any discussions about, or in the evaluation of, the information that was gathered and/or disseminated by the Sub-Committee in relation to the safety of commercial blood products?:

95. I don't know if the Medical Advisory Panel was involved any discussions about, or in the evaluation of, the information that was gathered and/or disseminated by the Sub-Committee in relation to the safety of commercial blood products. However, it is likely that the Medical Advisory Panel would have been the prime source of information the Sub-Committee relied upon about the safety in relation to commercial blood products as they would have had medical knowledge that the members of the Sub—Committee did not.

Question 22(iv) Was the information that was reported to the Council of the Society disseminated? If so, please set out to whom it was provided.:

96. I don't remember if the information that was reported to the Council of the Society was disseminated. The information may have been sent to the group delegates who formed the Council prior to the meeting, or at least been given in written form on the day. I do not know if it was disseminated to others. It would not have been disseminated further, at least until the Council had reviewed and approved any information. If it was useful

then it may have been disseminated to the membership, however I do not know the process for doing so, as, to the best of my recollection I was not involved in doing so.

*Question 23 In the Minutes of the Board of Trustee Meeting held on 11 July 1996, "Mr Barker explained that he had now received a copy of the HCDO draft guidelines on recommended products which now include the use of recombinant products [... and] The Blood Products Task Group would comment" [**HSOC0029689_006**]. Please detail the role of the Blood Products Task Group in commenting on, drafting or advising on HCDO guidelines on recommended products.*

97. I have reviewed **HSOC0029689_006**. Whilst I was present at the meeting recorded in that document, I do not have any independent recollection of the meeting or of these specific guidelines. **HSOC0029689** does not give any indication that the role the Blood Products Task Group would be taking other than commenting on the HCDO guidelines. Feedback of those comments may have been sent to the HCDO; I don't know. I don't think the Blood Products Task Group would have made any decisions regarding drafting guidelines, although it is possible, we may have made observations regarding the ease of understanding of the guidelines (for the lay person), especially if it was going to be seen by members of the Society. It is not stated who the guidelines were for.

Section 4: Communication and Dissemination of Information by the Society

4.1 Knowledge of Risk

Question 24 When you first joined the Executive Committee of the Society in 1984: .

Question 24(a) What did you know and understand about the risks of the transmission of hepatitis from blood and blood products? What were the sources of your knowledge? How did your knowledge and understanding develop over time?:

98. When I first joined the Executive Committee of the Society in 1984 I think, initially I knew very little about the risks of the transmission of hepatitis from blood and blood products, other than what I had been told by my Centre Director. To the best of my recollection, what I had been told was that there was a new hepatitis infecting Haemophiliacs; that little was known about it; and was that it was called non A, non B hepatitis. Its effects and outcomes at that time were unknown. My knowledge increased over time at the Haemophilia Society. As treatments progressed, so too did my knowledge.

Question 24(b) What did you know and understand about the risks of the transmission of HIV/AIDS from blood and blood products by others within the Society? What were the sources of your knowledge? How did your knowledge and understanding develop over time?:

99. I'm not entirely clear what is being asked in this question (in particular the phrasing "*by others within the Society*"). However, when I first joined the Executive Committee of

the Society in 1984, the only knowledge I had about the risks of transmission of HIV/AIDS from blood and blood products was from my Haemophilia Centre Director, the press and TV. I always considered anything from the TV and press to be a bit sensationalist and probably mildly inaccurate. My experience with the Fire Service being that the press and TV always exaggerated the facts and loved to get some morbid element into reports.

100. I don't think I would have learned anything about this topic from those on the Executive Committee directly, but would have gained knowledge through information from the Medical Advisory Panel and research from Trusts such as the Terrence Higgins Trust, who provided information to the Society about HIV patient treatments. Again, my knowledge increased over time at the Haemophilia Society. As treatments progressed, so too did my knowledge.

*Question 25. On 8 November 1984, "[i]n reply to a question from the Co-ordinator, the Executive Committee confirmed that there was no medical evidence available to show that UK products were in any way "safer" than imported ones, particularly from hepatitis or AIDS risk" [**HSOC0029476_042**]. How did the Haemophilia Society Executive Committee come to this conclusion? What were the resources that they relied on? How did this position develop over time?*

101. I have reviewed **HSOC0029476_042**. I am not aware where the Executive Committee got information to cause them / us to come to the conclusion that "*that was no medical evidence available to show that UK products were in any way "safer" than imported ones, particularly for hepatitis or AIDS risk".* This was only recently after my appointment to the Executive Committee and so, I believe, only the second or third Executive Committee meeting I had attended, following election to the committee.

102. If this was the belief at this time it was probably due to lack of evidence to demonstrate that imported product was not as safe. I do remember that as time progressed it became evident that these imported products were not as safe. I don't know where information came from regarding safety of blood products. I think as it became evident that imported products were less safe, the appropriate government departments were approached to encourage self-sufficiency in the early stages, and then the use of heat-treated products as soon as they became available. Although I don't recall the detail, I'm sure that the Society would have been one of the organisations that lobbied for this.

*Question 26. On 10 January 1985, the Executive Committee reported that it was "concerned that the introduction of heat-treated materials had been patchy [...] at least one Supra-Region had not yet introduced heat-treated materials" and that "there was wide disparity in the practice of individual centres". The Committee also expressed "concerns [...] that the reinforced leaflet for donors was not yet available while many Transfusion Regions had exhausted their supplies of the old leaflet. Many regions still had no warning notices for "at risk" donor groups" [**HSOC0029476_044**]. Please explain what happened in relation to*

these concerns and how, if at all, these concerns influenced the Haemophilia Society's policies on the safety of blood products. How, if at all, did this influence communications with members of the Haemophilia Society.

103. I have reviewed document **HSOC0029476_044**. I don't recall specifically the concerns raised by the Executive Committee on 10 January 1985 as set out in document **HSOC0029476_044**, that "*introduction of heat-treated materials … had been patchy*". However, I do recall being told that one (or more) of the regions was not using heat treated products when those were available and could be used. It is possible that the Executive Committee may have considered and discussed the issue and/or made some representations to whomever in the region was responsible (such as the Centre Director) to adopt the treatment, as the other regions had done. To the best of my recollection, I was not involved in such communications and am not aware of what action was taken. I do not know if this influenced communications with members more generally. Our members would already have been aware from the Society of the existence of heat-treated materials and would have been aware that they were not receiving those.

104. As for the concerns about a "*reinforced leaflet for donors*" I don't remember this leaflet or the comments in the Minutes. I don't know where the warning notices of 'at risk' donor groups were posted or how the Executive Committee came to know that there still were no warning notices in many regions.

105. I don't think the Society's policies were influenced by a region not using the Heat-Treated Product, the lack of a leaflet or Warning Notices not being put up somewhere.

*Question 27. On 7 February 1985 and 14 March 1985, the Executive Committee expressed concerns about AIDS and blood product supplies [**HSOC0029476_045** and **HSOC0029476_046**]. Please explain what happened in relation to these concerns and how, if at all, these concerns influenced the Haemophilia Society's policies on the safety of blood products. Did this influence communications with members of the Haemophilia Society?*

106. I have read through **HSOC0029476_045** and **HSOC0029476_46**. However, I am unable to recall what the concerns were about AIDS and blood product supplies, nor how this may have affected the Society's policies or communications with members, if at all.

*Question 28. In the Minutes of the Executive Committee Meeting, on 14 November 1991 [**HSOC0010385**] under the subheading 'Hepatitis', it is stated that, "...the [Project] 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." Could you please clarify:*

107. I have reviewed document **HSOC0010385**. Given the passage of time, I do not recall the detail of the meeting or the reason for the conclusion extracted by the Inquiry. I was also not, to the best of my recollection and based on the Minutes, a member of the Project Team that prepared the brief. However, I think it is likely that the Executive Committee had looked at the available information, possibly from the Medical Advisory Panel, and perhaps information from specialists at the time about Hepatitis C. Information at that time was limited. I understand that Haematologists believed liver biopsy in Haemophiliacs posed serious bleeding risks which may have been the basis for the view that biopsies were 'unethical'. At this time fairly little was known about Hepatitis C and the fear may have been that by making it a high-profile issue at that time it may cause a similar reaction to that at the beginning of HIV infections, being wide-spread fear and stigmatisation of those infected. Although I do not have any independent recollection of the meeting or the briefing, and was not part of the Project Team, I have set out responses to each of the Inquiry's questions below:

Question 24(a) Which medical experts were contacted? How did you decide who to contact?

108. Not being part of this project team, I don't know which medical experts were contacted, or how the decision was made as to who to contact. Who was contacted likely relied on knowledge or specialism.

Question 24(b) What did those experts tell the Project Team? Did they provide the Project Team with any journal articles or literature in relation to the known risks?

109. Not being part of that Project Team, I cannot advise what the experts told the Project Team, not whether they provided the Project Team with any journal articles or literature in relation to the known risks.

Question 24(c) Were minutes or notes taken of the discussions with the experts? If so, please provide copies of them.

110. I don't know if minutes of the discussions with experts were taken.

Question 24(d) Did all of the experts provide the same information to the Project Team or was different advice given by different experts? If so, how did the Project Team decide which expert advice to rely on?

111. Not being part of this Project Team, I don't know if the experts all provided the same information, or, if different views were given, how the Project Team decided which expert advice to rely on.

Question 24(e) How did the Project Team reach this conclusion and how long did it take to reach the conclusion?

112. Not being part of this Project Team, I don't know how the conclusion was reached, or how long it took to reach the conclusion.

Question 24(f) Was there any disagreement within the Team in reaching this conclusion?

113. Not being part of this Project Team, I don't know if there was any disagreement within the team in reaching the conclusion.

Question 24(g) Did some members of the Project Team have more influence than other members, and if so, who carried more influence than others?

114. Not being part of this project team, I don't know if any member had more influence than others, nor, if they did, who would have carried more influence.

Question 24(h) Please explain what was meant by "creating concern and worry where they need not exist". Did the Haemophilia Society change its planned communications to members because of this decision? If so, please explain how. In particular, were articles proposed for the Bulletin or other Society publications that were not published? If so, please set out the proposed author(s) and contents of any such proposed articles. Was this decision changed at any point in time? If so, please set out when and why.

115. I don't know what was meant by *"creating concern and worry where they need not exist"* as I understand these to be the words of the Project Team. I am not able to recall if the Haemophilia Society changed its planned communications to members as a result of this decision. I don't know if any articles were published or what the contents were in the Bulletin. If those decisions were made or changed, I don't know when or by who.

*Question 29. In 1994, in a memo to Graham Barker, you stated that you had "fears of another disaster if we persist in using blood products for the treatment of haemophilia. I have been saying this to various committees and to the medics, since recombinant products started trials, that we should promote these as being the safest" [**HSOC0023376**]. When and how did you come to believe that blood products could result in "another disaster"? Did other Executive Committee-Members share your concerns? What if any steps did you and/or your colleagues within the Society take in light of your views? Which committees did you express these concerns to? Which medics did you express your concerns to? What was their response?*

116. I have reviewed document **HSOC0023376** a memo from 1994 in which I state that I had *"fears of another disaster if we persist in using blood products for the treatment of haemophilia. I have been saying this to various committees and to the medics, since recombinant products started trials, that we should promote these as being the safest."*

117. As to when I came to believe that blood products could result in "*another disaster*" I don't know. I do know that there was a fear in the medical and scientific community that this could possibly happen again with Blood Products, and my fears would have been based around this.

118. I do recall having a personal fear of other viruses, as yet unknown, (as did some medical and scientific experts whose medical papers I had seen or discussed the issue

with a conferences, though I can recall any specific names or papers) which would, in the future, affect blood products and evade the purification processes that were being used. This was later borne out with the fears of the New variant CJD slipping past the purification processes

119. I was taking part in the Recombinant Factor 8 trial for Professor /Dr Edward Tuddenham, Centre Director of the Royal Free London NHS Foundation Trust, and had listened to him and followed the progress of the trial by talking to him at trial reviews. The term *"if we persist in using blood products"* was referring to the Haemophilia Community as a whole.

120. In my view, logic and the medical world were indicating that Recombinant Factor VIII was a far safer form of treatment than blood product, as it was not made from Human derived products, and therefore could not transmit Human viruses.

121. I do not know which, if any, other Executive Committee Members shared my concerns. However, I feel that, as we were all concerned that the safest products were available for our members, I am sure most would have been of this opinion.

122. I don't know what steps were taken were taken in light of my views, but obviously it was discussed within the Executive Committee. If I remember correctly, Haemophilia Centres and Health Authorities were encouraged by the Society to take up the use of the Recombinant Products by the Executive Committee/ the Society. I also believe that the Society lobbied the Government to provide Recombinant Factor VIII for everyone, though I cannot recall the timing of that and how directly (or close in time) my concerns were linked to the decision to do so.

123. As for which Committees I shared my concerns with, I had forgotten I was on the Services Committee, but **HSOC0023376** records that I raised the matter there, likely in the Blood Products Sub-committee, and latterly apparently via the Executive Committee.

124. As for the medics I raised my concerns with, that would probably have been in conversation with them at a meeting or conference of the Haemophilia Society. However, after the passage of time, don't remember who that would have been or what their response was. I do recall having rather a lively conversation with Dr Tony Aronstam, consultant haematologist Alton Treloar Haemophilia Centre about when Recombinant Products would be available and licenced (whilst I was on the trial). He insisting that it would take another 10 to 15years, when I had been told (by I think Dr Tuddenham) that it would be available within 2 years. When this took place, I could not say. My recall of some of this matter comes from my taking part in the Recombinant Trial, which thankfully was successful and did eventually became the treatment of choice, possibly due to pressure from the Haemophilia Society.

Question 30. When and in what circumstances did the Haemophilia Society become aware of any risks of transmission of vCJD associated with the use of blood and blood products? What were the sources of their knowledge? How did their knowledge and understanding develop over time?

125. I don't know when and in what circumstances the Haemophilia Society became aware of the possible risk of the transmission of vCJD via Blood Products, nor the sources of our knowledge. However, I understand this occurred around the time of the Bovine spongiform encephalopathy ('BSE'), more commonly referred to as 'mad cow disease', scare in the UK, (around 1996 based on an internet search). Over time no doubt we learnt more via the medical and scientific community, as well as more directly from the Medical Advisory Panel.

126. The possible risk of the transmission of vCJD did rather confirm my concerns of another virus slipping past the purification processes. As for any sources of knowledge, I feel sure it would have come from the medical and scientific community. From memory the medical and scientific community had fears that it would evade the purification process in use at that time. I really don't think anyone had any certainty about the outcomes of vCJD and transmission in blood products, and as far as I am aware this remains the case even today. I do not think by the time I left we really had a great deal of knowledge about vCJD. We are now some 25 years down the line, and thankfully, so far it has not become a problem.

Question 31. To the best of your knowledge, what actions did the Haemophilia Society take in relation to the risk of transmission of vCJD via blood products? What did the Haemophilia Society communicate to its members with regard to the risk of transmission of vCJD? What representations (if any) were made to Haemophilia Society members, the Government or the UKHCDO in relation to these risks? What was their response?

127. I don't remember what actions were taken by the Society in relation to the risk of vCJD via blood products. I would have thought that the Bulletin or other special publication would have been issued making our members aware of vCJD and the possible risk of transmission through blood products.

128. I don't know what representations were made to the Government or the UKHCDO. Although, if Recombinant Products at this time were not in general use, I feel sure it would have strengthened our case to the Government to make sure all Haemophiliacs were given Recombinant Products.

129. I don't know the Government's response, but I think it was not long after the discovery of the risk of vCJD in blood products that Recombinant became widely available to all.

4.2 Communication to Members

Question 32. 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.

130. I am afraid after the passage of time, I don't' recall who 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 my tenure. I do remember having sight of most of these publications, if they were presented at and/or discussed with the Executive Committee. Not all articles/reporting would have been presented to the Executive Committee. The articles that would have been put before the Executive Committee would have been those that contained medical or other information, for which we needed to consider the accuracy or impact, as opposed to reporting on social events or charity functions. Who composed, edited or selected the material, I don't know.

Question 33 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.

131. I have reviewed PRSE0000851, page 3 and Chris James' statement that *"the activities of the Society in disseminating information to its members were often spearheaded by haemophilia doctors"*. I don't necessarily remember this being the case. The doctors gave the information to us to share with our members. They were not involved in sharing that information themselves. However, it would seem logical that we would have passed information supplied by haemophilia doctors on to our members, and the doctors were providing the information because they felt the patients should know about it.

132. As for who these doctors were and their activities in disseminating information to the Society's members (if any), I don't remember.

Question 34. 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).

133. I don't remember the extent to which the haemophilia centre directors and members of the Medical Advisory Panel assisted in proposing and/or editing and/or selecting material for the Haemophilia Society's publications. However, I think they were probably asked to check content and asked to correct any inaccuracies.

Question 35. To what extent, if any, did representatives of pharmaceutical companies assist in proposing and/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).

134. I don't remember to what extent, if any, pharmaceutical companies assisted in proposing and/or editing and/or selecting material for the Haemophilia Society's publications. However, I think the only thing pharmaceutical companies were ever involved with in respect to publications was the financing of them, with the inclusion of a small logo or sponsored by "…xxxx pharmaceutical company".

Question 36. 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?

135. I don't remember how the Haemophilia Society selected or identified contributors and interview subjects for its publications. I would have thought we looked at information sent to us, such has reports or updates from experts in their respective areas which related to treatment of haemophiliacs, or gone to a medical expert in the area of a publication we intended to produce.

136. I do not recall if there were criteria for someone to be able to write an article for the Society publications.

Question 37: 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.

137. I don't know to what extent the Haemophilia Society verified medical and scientific information and/or opinions provided by contributors to its publications. I would have thought, if it came from a source we knew to be reliable, we may have accepted it without verification. If it was a new or unknown source, I feel sure we would have asked someone in that area of expertise we knew and trusted to verify it before use. Those experts may be from the Medical Advisory Panel, but there were also clinicians we would approach outside the Medical Advisory Panel for their opinion, such as physios that had a specialism in treating patients with haemophilia. I cannot recall any of those clinicians names.

Question 38. 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.

138. I don't know if the Haemophilia Society received direct inquiries from the public or members who required advice with regard to the safety of blood products specifically. I know we did receive enquiries from the public and our members. However, I was not involved in receiving, responding to or overseeing those queries. It would have been the Society staff that did so. I'm therefore also unable to advise what resources, if any, the Society relied on to enable a response or what advice or information the Society had and from whom that had been provided

*Question 39. On 10 October 1985, Mr Knight reported to the Executive Committee "on the difficulty of keeping abreast of events and maintaining essential communication needed to ensure that policy matters are settled speedily. He stressed that very often those decisions had to be made on the spur of the moment in response to medical calls for urgent reply" [**HSOC0029476_053**]. What was Mr Knight referring to when he referred to decisions being made "on the spur of the moment"? Who were the "medical calls for urgent reply" being received from? How were these decisions made? What advice was taken in order to enable decisions to be made? What was communicated to members? Was medical advice provided to members of the public by the Haemophilia Society without advice first having been sought from the Medical Advisory Panel?*

139. I have reviewed document **HSOC0029476_53**. Given the passage of time, some 36 years, I don't remember the meeting recorded in that document or the statement made by Mr Knight during that meeting. I therefore do not recall what Mr Knight was referring to when he referred to decision being made "*on the spur of the moment"* or who the *"medical calls for urgent reply"* were being receiving from. Neither am I able to recall how the decision were made, the advice taken to enable decision to be made or what was communicated to members.

140. I do not believe that medical advice would have been provided to members of the public by the Haemophilia Society without first having sought advice from the Medical Advisory Panel, unless it was outside their expertise and then independent expert view would have been sought before dissemination.

4.3 Communication on Hepatitis C

Question 40. To the best of your knowledge, what information and advice did the Haemophilia Society provide on the:

Questions 40(a): Risk of Non-A Non-B Hepatitis/ HCV infection from blood products? Please detail the method of communication, details and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how;

141. I don't remember what information and advice was provided by the Society on the risk of Non-A Non-B Hepatitis/HCV infection from blood products. Various articles would have been in Bulletins and possibly other small one-off publications. I do not have copies of any of these. Changes over time may have been the introduction on the web site, but I do not recall.

Question 40(b): Health implications of Non-A Non-B Hepatitis/ HCV infection? Please detail the method of communication, details and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how; and

142. I don't remember what information and advice the Society provided on health implication of Non-A Non-B Hepatitis/ HCV infection. Information would probably have been included in Bulletins and other one-off publications, as and when any relevant and useful information became available. I do not have any of these. Changes over time may have been the introduction of the web site, again I do not recall.

Question 40(c) Prevalence of Non-A Non-B Hepatitis/HCV infection amongst haemophiliacs? Please detail the method of communication, details and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how:

143. I don't remember what information and advice the Society provided on the prevalence of Non-A Non-B Hepatitis/HCV infection amongst haemophiliacs. Again, I would assume that various articles would have been in Bulletins and other one-off publications as and when any relevant information became available. Changes over time may have been the introduction of the web site, again I do not recall.

Question 41. Considering your answer to question 40, 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:

144. Unfortunately, given the passage of time I am unable to recall the basis for the communications and advice provided by the Haemophilia Society to members about Non-A/Non-B Hepatitis/HCV during my tenure. However, I have provided individual responses to the Inquiry's questions below:

Questions 41(a) To what extent (if at all) were medical professionals relied upon to produce the advice and opinions in these documents?

145. I don't remember to what extent (if at all) medical professionals were relied upon to produce advice and opinions in these documents, but assume most if not all of our information would have come from medical professionals.

Questions 41(b) Who provided that advice?

146. I don't know who provided that advice.

Questions 41(c) Who, and how was it, decided which medical professionals should be approached for any such advice and what advice should be sought?

147. I don't remember who and how it was decided which medical professionals should be approached for any such advice and what advice should be sought. However, I would have thought that the advice would have come from medical professionals with the appropriate knowledge, probably based around members of the Medical Advisory Panel.

Questions 41(d) Who, within the Haemophilia Society, sought any such advice and who did the medical professional provide the advice to?

148. I don't remember who within the Society sought any such advice, but it would probably have been a designated member of Staff. I do not recall who the medical professionals provided the advice to.

Questions 41(e) What was their advice in relation to each of the communications you have set out in answer to question 63 above?

I'm unsure which question you are referring here. You refer to my answer to 'question 63 above', but this is only question 41. If referring to 40. I don't know what their advice was in relation to each communication.

Questions 41(f) If advice was received, was that advice edited? If so, why, and by whom, was it edited?

149. I don't know if advice was edited, or by whom. However, if it was edited, I feel sure it would have been to place it into more 'Lay Terms' prior to issuing any advice, especially to members.

Questions 41(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.

150. I don't remember if the Society received advice from other medical professionals or what advice that might have been received. If we did received advice from other sources, and if conflict had arisen, I believe a resolution of any conflict would have been sought and verified, probably by other qualified medical professionals. I have no recollection of this happening.

4.4 Communication to Healthcare Professionals

Question 42. 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.

151. I don't remember any activities the Haemophilia Society conducted to give information to healthcare professionals and if this changed over time.

*Question 43. 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?*

152. I have reviewed document **HSOC0010277**. I don't remember this memo entitled "Medical Advisory Panel" which states that "*Society's lobbying might be more effective if endorsed by a Medical Advisory Panel….. health professionals, staff in smaller Centres and some patients might fall into this category*". I can only think that endorsement may have been felt to offer weight to Lobbying.

153. To the best of my knowledge, the Society did not lobby staff in smaller centres. My reading of this memo is that we sought endorsement from the groups mentioned to support the Society's lobbying, rather than lobbying those groups themselves.

*Question 44. 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.*

154. I have reviewed document **HSOC0029689_004**. I do not specifically recall the Board of Trustees meeting held on 9 May 1996, given the passage of time. I have, however, provided my responses to your questions below.

Questions 44(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?

155. I don't remember the Society "making recommendations for actions by Centres" or seeking to influence the UKHCDO policy and practices. To the best of my recollection, I was not involved in any such practice.

Questions 44(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.

156. I don't know why the Society would have interviewed patients. To the best of my recollection, I was not involved in any such practice and would not have thought we would have interviewed patients, nor had the right to do so. I cannot provide details of the circumstances or purposes of those interviews, if they occurred.

Section 5: Pharmaceutical Companies

5.1 Financial Relationships

Question 45. 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.

157. I don't remember the full extent of reliance by the Society on pharmaceutical companies' financial contributions. I do remember that they did on occasion provide financial assistance for Conferences and Publications. If a pharmaceutical company approached us to help fund a conference, they would be allowed a 'booth/stand' at the conference. If one company contributed to a conference, the Society would approach other pharmaceutical companies to invite them to come to the conference as well. If a pharmaceutical company funded or contributed to funding of a publication then their logo or company name would be put on that publication.

158. I don't remember the level and nature of funding, nor the detail of how it changed over my tenure. However, I do know that during my time as a Trustee the practice of allowing 'booths' at conferences was no longer allowed, although when it stopped, I don't know. Whether this was by law or advice / directive from the Charity Commissioners I do not know.

159. Activities that were paid for at least in part would have included the Chairman's Conference, possibly the Bulletin and other publications. I don't recall staff being paid for by the pharmaceuticals, I don't think we would have entertained them funding staff as this person would effectively have been their employee in our organisation. I can't remember the levels of funding, and I don't remember if it was full or part funding.

160. To the best of my recollection, I had no involvement with liaising with the pharmaceutical companies or the arrangements for financial contributions from them.

Question 46. Was the Society's relationship with BPL different to its relationship with the pharmaceutical companies? If so, please explain how.

161. I don't know if the Society's relationship with BPL was different to its relationship with the pharmaceutical companies. However, as they were not a commercial pharmaceutical company, I do not think it would have been possible for BPL to provide the Society with any financial assistance.

162. On reflection, the Society had an open and transparent relationship with BPL. As set out in my response to question 21(j), BPL provided us with information and kept us up to date on developments in the processes used and safety of blood products. I also recall being invited to attend the laboratory to see, first hand, the quarantine processes that were used on blood products. I do not recall being invited to any other pharmaceutical laboratory. I would think we would not have shared anything we learned from them with others, without their express permission

Question 47. 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.

163. I don't know how or when the financial relationships between the Society and pharmaceutical companies were formed, who prompted the relationship, or who the points of contact were. I assume the point of contact was probably via the Chief Executive. As for the method of communication, I would have thought Phone, Letter or latterly email.

Question 48. 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?

164. I think fundraising activities changed over my tenure, but in what sequence I can't remember.

165. There was a reliance on donations, membership fees and legacies in the early days (I don't think pharmaceutical companies would have been involved prior to the introduction of commercial blood product into our health service). At what stage the pharmaceutical became part of funding I don't know, but assume it would have been around the time of their products being used in the NHS.

166. With the arrival of HIV we received a grant from the government. When funds from pharmaceutical companies stopped, I think about that time we employed an in-house fund raiser, Trust funds (such as the Joseph Rowntree Foundation and the Roald Dahl

Foundation) were approached as a source of funds, and Organisations like Jeans for Genes, and any national fund-raising function that we might have been eligible for financial assistance from. We also received funds from members, local groups, and from member fund raising activities, like London marathon, Sky dives, Swimming marathons etc.

Question 49. 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?

167. I don't recall and, to the best of my recollection was not aware of, the differences in the Society's relationships with the different pharmaceutical companies (if any), whether some companies donated more, whether they had different expectations of the Society or if they wanted to fund different activities or functions.

Question 50. 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?

168. I don't know what the motivations or expectations, if any, were of the pharmaceutical companies who donated to the Society. My assumption would be to try and make patients aware of and interest them in their products, maybe in the hope they would ask their Centre to use their product.

169. As far as I am aware, there was nothing expected or received directly from the Society for donation, other than the ability to have a stall at a conference, or their company name on a publication, as mentioned in response to question 45 above.

Question 51. 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.

170. To the best of my knowledge and recollection, I don't think the Haemophilia Society assisted pharmaceutical companies to promote their products or public image. Any form of association with them, as far as I can remember, was limited to a small display at Conferences and a small acknowledgement / logo on any publication funded by them (as mentioned above).

171. I cannot recall specifically which pharmaceutical companies (or their products) attended conferences or had logos on publications.

Question 52 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.

172. I don't know if the Haemophilia Society published or disseminated any articles or publications in exchange or with the expectation of receiving financial contributions or any other benefit by pharmaceutical companies. To the best of my knowledge and recollection, that did not occur. It is possible that raw data was received from a pharmaceutical company and included in an article, though I cannot recall any specific instances of that happening, and I do not have any knowledge that would have been in exchange for or with the expectation of receiving financial contributions.

Question 53. 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.

173. I don't know if the Society refrained 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. However, I cannot imagine that we would not have published something at the request of a pharmaceutical company in favour of receiving a financial contribution.

5.2 Other Relationships

Question 54. 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.

174. I don't know, if the Society relied on pharmaceutical companies for assistance or support, other than financial contributions. To the best of my knowledge, that was not the case.

Question 55. 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?

175. I don't remember what relationship the Executive Committee-members of the Society had with pharmaceutical companies. I myself did not have any particular relationship with those companies. I do not recall any other relationship with representatives of the pharmaceutical companies. I do recall Norman Pettit, lead representative for BPL, attending meeting at the Society. However, I do not recall in what role or for what

purpose that he did so. I understand that Mr Pettit has unfortunately now passed away. To the best of my knowledge and recollection, no representatives ever joined the Haemophilia Society Executive Committee whilst working for or after leaving a company.

176. I never saw a membership list, so it is possible a representative from a pharmaceutical company could have been an ordinary member.

*Question 56. 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.]*

177. I have reviewed **BPLL0002037**.

178. To the best of my knowledge and recollection, I don't believe the Haemophilia would have relied on a pharmaceutical companies' assurances or opinions on the safety of their blood products. As for the content of **BPLL0002037** it looks to me like David Watters was asking for information about any warnings that had accompanied their products, rather than seeking assurance on the safety of blood products. Who he is requesting the information for is not stated. I also don't understand how the warnings from pharmaceutical companies relate to the Governments obligation to warn people, as is referenced by Mr Watters in this memo.

Section 6: Relationship with the Government

Question 57. 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?

179. I don't know about the Society's relationship with the Government and individuals in public office, who the main points of contact were, how those relationships were formed, or if there were regular meetings. I was not involved with the Society's interactions with, and representation to, the Government. This was done by members who had knowledge of the political system and Government such as Simon Taylor and possibly David Watters and Clive Knight.

Question 58. 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.

180. As set out in response to question 57 above I was not involved with the Society's interactions with, and representation to, the Government. This was done by members

who had knowledge of the political system and Government. I don't remember who they were so cannot assist with this question.

6.1 The Supply of Imported Blood Products

Question 59. 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.

181. I don't know who was responsible for deciding the Society's positions and representations made to the Government regarding the use and supply of imported blood products. I would have thought this would have been discussed and we would have made those decisions in the Executive Committee. I cannot specifically recall any such discussions or decisions.

Question 60. What were the key issues that the Society pursued?

182. I don't recall specifically, but assume the key issues related to supply of imported blood products pursued by the Society would have changed over time due to changes in treatments and knowledge. Generally, I believe these would have been: self-sufficiency; promotion of the use of heat-treated products; I think there was some other viral inactivation process introduced; and with the advent of Recombinant products, the supply and the use of this product for all. With the introduction of Recombinant products, the risk of imported blood products was significantly reduced. As long as factories were sterile the risks were negligible no matter where the product came from.

Question 61. To the best of your knowledge, please detail the Haemophilia Society's policies with regard to communication on the safety of imported blood products. What information did the Haemophilia Society communicate to members? How did these communications develop over time?

183. I don't recall any of the Society's policies regarding communication on the safety of imported blood products. I feel certain we would have communicated about the safety of imported blood products to our members, but how, when and by what method I can't remember. I cannot comment on how those communications developed over time.

*Question 62. On 7 October 1990, the Policy Committee agreed on the Haemophilia Society's "Blood Products Policy" that "upholds the principle of a voluntary donor based system within the United Kingdom adequate to ensure self-sufficiency [....] The Society acknowledges that until this goal is achieved it remains necessary to use certain imported products from paid donor sources" [**HSOC0010398**]. Please comment on this. How did the Haemophilia Society come to agree on this policy? Why did the Haemophilia Society consider it necessary to continue the use of imported blood products? Did the Haemophilia Society approve of specific "imported products from paid donor sources"? If so, which ones? [You may also be assisted by **HSOC0017203**]*

184. I have reviewed **HSOC0010398** and **HSOC0017203**. Reading **HSOC0017203** came as a shock to me as I don't remember being on the Policy Committee. This was 30 years ago. However, from reading the various documents I can now see I was a member of this committee, at least temporarily.

185. Although I cannot recall those meetings, so cannot specifically comment on how the Society came to agree on the policy or why the Society considered it necessary to continue the use of imported blood products, my view would be that the principal of voluntary donor-based system was preferable as there was no financial benefit to giving blood. Paid donors were often those with very poor health lifestyles, often desperately needing money and gave blood regularly for financial gain, often at different donor centres. My views on this are partially informed by a book called Blood, by Douglas Starr.

186. Although I do not recall the discussions at the time, I assume the need for continued use of products by pharmaceuticals using paid donors can only be because of the severe short-fall in UK donor-based products. If there was a shortage, many would have suffered pain, disability and lives could be have been lost even earlier due to the non-availability of clotting factors. I think the facts of the short-fall probably drove the need for this policy.

187. Reading **HSOC0010398**, it is apparent that this policy was only seen as an interim policy pending the introduction of Recombinant products. It would also appear from this document that monoclonal antibody techniques were being used in the purification of blood products. From memory, I think this was seen as the safest method of producing the safest blood products at that time. I don't remember and don't believe the Society have approved any specific products from paid donor sources.

Question 63. 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.

188. I don't know if the Society received assurances by the Government or individuals in public office on the use and supply of imported blood products.

6.2 Self-Sufficiency

Question 64. Please identify who was responsible for determining the Society's position in relation to self-sufficiency.

189. I don't remember who was responsible for determining the Society's position to self-sufficiency but my assumption would be the Executive Committee, as it was the Executive Committees role to consider such issues and come to decisions on the

overall position of the Society. I do not recall specifically having those discussions or their content.

Question 65. How and when was the Society's position regarding self-sufficiency communicated to the Government? If this changed over time, please detail when and why.

190. I don't know how and when the Society's position regarding self-sufficiency was communicated to the Government. However, although I don't know dates of any changes in our position, I remember we pressed for the following as they became available in the interests of our members: first, heat treated products; followed by the monoclonal antibody purified product; then finally Recombinant for all as it became available. The need for those products was driven by the failure to achieve self-sufficiency, as we were looking to promote ways to ensure the safety of any imported product.

Question 66. To the best of your knowledge, did the Government provide any assurances to the Society on its ability and aim to achieve self-sufficiency during your tenure? If so:

Question 66(a) Please provide details, identifying assurances that the Society received, when they were received and by whom they were given.

Question 66(b) Did the Government place any caveats on these assurances?

Question 66(c) Did the Haemophilia Society rely on these assurances and if so how?

Question 66(d) Were any actions taken by the Society to verify the assurances?

Question 66(e) Were these assurances communicated to members? If so, how?

191. I don't recall if the Government provided any assurances to the Society on its ability and aim to achieve self-sufficiency during my tenure. To the best of my knowledge and recollection, I don't believe any assurances regarding self-sufficiency were ever forthcoming. I am therefore unable to comment further on questions 66(a) – (e).

6.3 Reduction of Risk of Blood Products

Question 67. 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?

192. I don't know who was responsible for determining the Society's position in regard to reducing the risk of blood products, but believe it would have been a decision made by the Executive Committee as a whole. I believe that position would have been as described in question 65 above.

Question 68. What were the key issues that the Society pursued?

193. To the best of my recollections, the "key issues that the Society pursued" relating to the reduction in risk of blood products, would have been the call for the safest blood products for our members. Over time what 'the safest product' was would have

changed, being: the use of freely donated blood / plasma for the production of clotting products from screened donors, self-sufficiency in the supply blood derived clotting products, the availability and use of heat treated products, the availability and use of monoclonal viral inactivation products and ultimately the availability and use of Recombinant product for all.

Question 69. 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.

194. I don't know how, when and with whom the Society's position relating to reducing the risk of blood products was communicated to the Government, nor if this changed over time.

Question 70. 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.

195. I don't know if any assurances were given by the Government in response to the communication of the Society's position.

Question 71. 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.

196. I don't know what decisions and actions were taken by the Society, based on information provided by the Government, nor if this changed over time.

Question 72. 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.

197. I don't know if the Society relied on assurances by the Government or individuals in public office on the safety of blood products.

6.4 Campaign for Compensation

Question 73. When did the Haemophilia Society begin campaigning for compensation for (a) haemophiliacs infected with HIV/AIDS (b) haemophiliacs infected with HCV/Hepatitis C as a result of contaminated blood products ("campaigns for compensation")?

198. I don't know when the Society began campaigning for compensation for (a) haemophiliacs infected with HIV/AIDS; or (b) haemophiliacs infected with HCV/Hepatitis C as a result of contaminated blood products.

Question 74. Please identify who was responsible for determining the Society's position in relation to campaigns for compensation.

199. I don't know who was responsible for determining the Society's position in relation to campaigns for compensation. However, I would that thought that would have been the

Executive Committee as it was the Committee's role to make decisions on issues of that kind. I do not recall those discussions or their content.

*Question 75. What prompted the Society to begin campaigning for compensation for haemophiliacs infected with HIV/AIDS? [**BAYP0000010_144; PRSE0007003**]?*

200. I have reviewed **BAYP0000010_144** and **PRSE0007003**.

201. I don't recall what prompted the Society to begin campaigning for compensation for haemophiliacs infected with HIV/Aids.

202. **BAYP0000010_144** would appear to set out why the campaign was started. Although I cannot recall the thinking at the time, I believe we must have felt members deserved some form of recompense. I seem to remember the mood of the membership was that there should be some form of recompense for HIV infection through contaminated blood products. This is likely what triggered, or at least contributed to, the decision to begin campaigning for compensation.

203. **PRSE0007003**, being the Preliminary Report of the Penrose Inquiry in Scotland, was not released until 2010. I believe I ceased being a Trustee in 2003 or earlier and I never read the report.

Question 76. What were the goals and priorities of the campaigns for compensation for haemophiliacs infected with HIV/AIDs?

204. To the best of my recollection, the goals and priorities of the campaigns for compensation for haemophiliacs infected with HIV/AIDS were to achieve some form of recompense and/or compensation for those infected.

Question 76(a): How were the goals set?

205. I don't recall how the goals were set.

Question 76(b): To what extent (if any) did the Haemophilia Society achieve these goals during your tenure?

206. A one-off ex-gratia payment was made to be distributed to those persons with haemophilia who have been infected with HIV through blood product. The MacFarlane Trust was jointly set up as a charity (and then became a stand-alone charity) between the Society and the Government as a means of administering the payments to those infected with HIV through contaminated blood products. This was, on my recollection, because the Government did not want the Society to administer the money. I am not sure why. The MacFarlane Trust continued as a charity until the Infected Blood Scheme was set up. Any remaining funds, I believe went to the Terrance Higgins Trust.

207. I recall that many (if not all) members of the Executive Committee would have liked a larger payment or a more regular payment scheme set up for ongoing support.

However, I recall that the Government position was that we could not expect to receive or achieve more and our legal advice was that this was probably the best we would get from the Government at the time. I think it was felt by the Executive Committee that at least something had been achieved.

Question 76(c): Were the Society's goals communicated to the Government? Was there a response?

208. I don't know if the Society's goals were communicated to the Government or if there was a response.

Question 76(d): What statements and assurances were made by the Government to the Society in relation to the compensation? Who provided any such statements or assurances? If this changed over time, please detail when and why.

209. I don't know what statements and assurances were made by the Government to the Society in relation to the compensation, who provided such statements or assurances, if any, or if this changed over time.

Question 76(e): Were these statements or assurances relied upon? If so, how?

210. I don't know if statements or assurances were relied upon, or how.

Question 77. Considering your response to question 76, to what extent (if any) was the campaign for compensation for haemophiliacs infected with HIV/AIDS informed by the views of the Society's membership? Did these differ from the views of the Haemophilia Society Executive Committee, as you understood them?

211. I believe that the campaign for compensation was informed by the views of the Society's membership. However, not all members agreed with how we went about that. I suffered some verbal abuse and physical threats from two members who were not happy that I was not willing to put myself in front of the cameras for the campaign. After this I tended to step well back from any form of one-to-one discussions with the membership.

212. I am not sure if the opinions differed greatly. I do remember some members were not satisfied with the outcome of the campaign. Separate groups for pursuing compensation had been, or were, formed. Some of those must have included members of the Society, as I recall them expressing their discontent at Society meetings. I do not recall the specifics of the views they expressed, but generally I think that they wanted the Society to pursue greater financial payments.

213. I do remember that we (the Executive Committee) felt we had achieved what was possible at that time, but that it really was not all we would have wished for (we would have liked a larger payment or more ongoing regular payments). I think the membership probably felt the same.

*Question 78. In 1994, the Services Committee considered a proposal by the Hepatitis Committee for a Hepatitis C 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**]. You "expressed the fear that in the public eye hepatitis would take on the same dimension as HIV, and stated that the Society should discourage people from pursuing the idea of Litigation". Several other members of the Committee also disagreed with the proposal on the basis of the publicity that would result from such a campaign. Please explain:*

214. I have reviewed document **HSOC0023353** and my statement that I feared *"that in the public eye hepatitis would take on the same dimension as HIV, and stated that the Society should discourage people from pursuing the idea of Litigation".*

Question 78(a): What you feared would result from a publicity campaign;

215. I think my fear about a publicity campaign was that those who had been infected would find themselves stigmatised once again, as had been the case, and still was from the HIV infection.

Question 78(b): Why you considered that the Society should "discourage people from pursuing the idea of Litigation";

216. I don't really remember why I considered that the Society should "*discourage people from pursuing the idea of Litigation".* However, I think this was likely based around the conditions attached to the HIV settlement: part of the agreement was that those infected would not pursue the Government (or future Governments) for compensation in relation to infection from contaminated blood products. The specific language used will be recorded in the settlement documentation, but I do not have a copy of that. I was likely concerned that members could find themselves incurring financial losses, attempting to litigate, but being barred from doing so, would not have any success.

Question 78(c): Why members of the Committee were concerned with the publicity that would come from a Hepatitis C Campaign.

217. I do not recall why members of the committee may have been concerned with the publicity that would come from a Hepatitis C Campaign. However, it may have been because they shared the same opinion as myself set out in response to question "78(a)" above.

Question 79. What was the Haemophilia Society's position (if any) with regard to compensation for haemophiliacs who were infected with HCV/HCV as a result of contaminated blood products during your tenure? If this changed over time, please detail when and why.

218. I don't know what the Society's position (if any) was with regard to compensation for haemophiliacs who were infected with HCV as a result of contaminated blood products during my tenure. However, I seem to remember the issue was largely

sidestepped/avoided by Government, and may have been so because of the agreement with the HIV ex-gratia payment, which I believe said that no further payments/compensation would be made for similar infections. I may be wrong. I have set out my answers to sub-questions 79(a) – (c) below.

Question 79(a): Was this communicated to the Government? Was there a response and if so what was it?

219. I don't know if a position was communicated to the Government, my recollection was that the issue was largely sidestepped/avoided by Government, so I would guess this must have been communicated to them at some point for me to have formed that view.

Question 79(b): What statements and assurances were made by the Government to the Society in relation to compensation? If this changed over time, please detail when and why.

220. I don't know what statements and assurances, if any, were made by the Government to the Society in relation to compensation or if those changed over time.

Question 79(c): Were these statements and assurances relied upon? If so, how?

221. As I don't know what these statements and assurances, if any, were so I can't answer this question.

*Question 80. In the Minutes of the Board of Trustees meeting held on 21 June 2002, the "Trustees agreed that it was important to explain to members that The Society's financial situation requires that the level of resource devoted to the campaign be reduced. Experience indicates that there is little or no hope of winning a public inquiry or recompense for HCV" [**HSOC0029689_045**]. Please comment. Why did the Haemophilia Society come to the conclusion that there was "little or no hope of winning a public inquiry or recompense for HCV"? What (if any) representations by the Government did the Haemophilia Society rely on? [You may be assisted also by **HSOC0029689_042** and **HSOC0029689_041**].*

222. I have reviewed **HSOC0029689_054**, **HSOC0029689_042** and **HSOC0029689_041**.

223. I don't recall this meeting and do not know why the Society came to the conclusions that there was "*little or no hope of winning a public inquiry or recompense for HCV*". However, on reading the Minutes contained in **HSOC0029689**, I would assume that, as the Society was experiencing a large shortfall in income, that economies had to be made.

224. From what I do remember, any communication with the Government, be it Ministers/MP's or Civil Servants were exceptionally negative (they did not want to engage with the issue) and it became apparent that there would be no chance of any form of Inquiry or recompense. That was, perhaps the basis for the statement.

225. I don't know what representations by the Government, if any, the Society relied on. On reading **HSOC0029689_042** Minutes of meeting 16th January 2002, point TO2.04 c &

d explains this question far better than I can remember. Additionally, on reading **HSOC0029689_041** Minutes of 29th November 2001, TO1.78. I feel it quite clearly explains the answer to the points raised in this question. I was not able to attend this particular meeting so cannot comment further.

Question 81. To what extent (if any) was the campaign for compensation for haemophiliacs infected with HCV/Hepatitis C informed by the views of the Society's membership? Did these differ from the views of the Haemophilia Society Executive Committee, as you understood them?

226. I don't remember to what extent (if any) the campaign for compensation for haemophiliacs infected with HCV/Hepatitis C was informed by the views of the Society's membership. I presume we would have listened to the membership and, if practical, would probably have acted on those views. However, if or how they differed, I don't remember.

6.5 Campaign for a Public Inquiry

Question 82. What role did the Haemophilia Society play in seeking a public inquiry? When did the Haemophilia Society consider an inquiry was a possible course of action? Why was that decision made then? Please set out chronologically the Society's campaign and or involvement in the campaign for an inquiry, including any discussions with the Government and any assurances that were received from Government.

227. I don't remember what role the Society played in seeking a public inquiry. I would have thought that members of the Executive Committee were in communication with relevant persons in the Government and Civil Service who could influence the setting up / ordering a public inquiry. I was not one of those members and cannot recall who that would have been.

228. I can't remember when the Haemophilia Society considered an inquiry was a possible course of action, or why the decision was made. However, I am sure we felt there should be a public inquiry, from the time of the discovery of the link between contaminated blood products, and persons with haemophilia being infected with HIV. Having no memory of this, I can't set out chronology of the Society's campaign or involvement in the campaign for an inquiry, nor any discussions with the Government or any assurances received from the Government.

*Question 83. In the Minutes of the Board of Trustees meeting held on 1 May 2002, the Trustees agreed that "the Society's campaign for a public inquiry should be put on hold" [**HSOC0029689_044**]. Why did the Haemophilia Society decide to put on hold the campaign for a public inquiry? What (if any) representations by the government did the Haemophilia Society rely on in this decision? [You may also be assisted by **HSOC0029689_042**, and **HSOC0029689_041**].*

229. I have reviewed **HSOC0029689_044**, **HSOC0029689_042** and **HSOC0029689_041**.

230. I don't remember why the Society put the campaign for a public inquiry on hold. However, reading **HSOC0029689**, Minutes of a Trustee meeting 1st May 2002, I can only assume it was at least in part due to the Society's financial situation. Although why I supported it being dropped initially, I don't know.

231. **HSOC0029689_044** records that I was in agreement with the proposal of Simon Taylor to put the campaign on hold. I do not recall why. It may have been the fear that our other core services were likely to suffer as a result of continuing. Some projects, according to **HSOC0029689_42** Minutes of Trustee meeting 16th January 2002 TO2.04 d. contains a reference to 2 projects for women and youth development, had been cancelled due to lack of funds.

232. I do not recall what, if any, representations by the government the Haemophilia Society relied on in this decision.

Section 7: Other Issues

Question 84. 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?

233. To the best of my knowledge, at no point did Haemophilia Staff and committee-members purposefully or existentially destroy documents relevant to the Terms of Reference of the Infected Blood Inquiry.

Question 85. 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.

234. I have no other matters I believe may be of relevance to the Infected Blood Inquiry, having regards to its Terms of Reference and to the current list of issues.

Statement of Truth

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

Signed GRO-C

Dated 14th May 2021