Witness Name: Bernard Manson
Statement No: WITN3092001
Exhibits: WITN30920002-0032
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BERNARD MANSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 19 November 2020.

I, Bernard Manson, of GRO-C will say as follows: -

1. My evidence covers the period from November 2011 to November 2015 when I was Chair of the Haemophilia Society, ie some 5 to 9 years ago. I have tried to differentiate between where (a) my memory is clear (or I am relying on documents) and (b) I am giving a reasonable overview from memory but cannot remember details. If the Inquiry sees a particular statement as important and the wording does not make clear whether it is in category (a) or (b), I would be pleased to review this and advise my confidence in its accuracy or, if relevant, supply the underlying document.

2. I use the term "Contaminated Blood" in the sense in which it is used by the community of those infected and affected by the NHS's historic treatment of patients using blood transfusions and blood products contaminated with viruses. That is, it is a short-hand expression to encompass the whole history of these events from the 1970s through to the time covered by my statement, including all aspects of the initial infection and subsequent treatment and support and all actions of government, clinicians, and others who have been involved in a relevant capacity, without judgement as to details and responsibilities.

3. Note that where a question asks me to cross-refer an answer to a numbered paragraph in my statement, I have instead cross-referred to the question which the

relevant paragraph answers. This is because the Inquiry may ask me to add additional information after I submit my initial draft statement, and this could then affect the paragraph numbering. Referring to question numbers removes this potential for creating errors.

4. The following abbreviations are used in my replies:

APPG	All Party Parliamentary Group on Haemophilia and Contaminated Blood
CAG	Clinical Advisory Group
CRG	Clinical Reference Group
CEG	Clinical Experts Group
DoH	Department of Health
EHC	European Haemophilia Consortium
HA	Haemophilia Alliance
HS	Haemophilia Scotland
HSMC	Haemophilia Scotland Management Committee
UKHCDO	UK Haemophilia Doctors Organisation
SECC	Scottish Exhibition and Conference Centre
WFH	World Federation of Hemophilia (note USA spelling)

SECTION 1: INTRODUCTION

(Q1) Please set out your name, address, date of birth and professional qualifications

5. Bernard Manson.

6. GRO-C

7. GRO-C 1955.

8. FCCA (Fellow Member of Association of Chartered Certified Accountants) 1992

9. I would want my address and exact date of birth redacted from the public record.

(Q2) 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.

Career Summary from my CV

2018 to now	Number Champions (Educational charity) *Chair, Acting CEO (unpaid)*
2011 to 2018	Ablon ltd (Consultants) *Consultant for various business clients*
2006 to 2011	Santander Bank Plc *Business Development Manager, UK Corporate Banking*
2003 to 2006	Ablon LLP (Consultants) *Consultant for various business clients*
1993 to 2003	Barclays Bank PLC *Divisional Finance Director in Investment and Retail banks.*
1991 to 1993	Bernard Manson Associates (Consultants) *Consultant for various business clients*
1985 to 1991	Chase Manhattan Bank, N.A. *Vice President in Risk Management*
1984 to 1985	T & ACS Ltd (Software house) *Project manager*
1983 to 1984	Nikuv Ltd (Software house)

	Analyst/programmer
1978 to 1982	Harlow & Jones Ltd (Metal traders) From *graduate trainee* progressed to *Assistant to Finance Director*

(Q3) Please set out your membership, past or present, of any committees, groups, associations, societies or working parties relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

10. The Haemophilia Society, Chair, November 2011 to November 2015.

11. This was an unpaid role.

12. In my answers to the questions below in Section 3 and elsewhere, I elaborate in detail on my role as Chair, including subsidiary and associated roles and responsibilities which derived from this.

SECTION 2: PREVIOUS EVIDENCE

(Q4) 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.

13. I have neither provided nor been asked to provide such evidence nor have I been involved with such inquiries, investigations, or litigations.

SECTION 3: YOUR ROLE AND THE STRUCTURE OF THE HAEMOPHILIA SOCIETY

(Q5) Please confirm and outline your role and the responsibilities within the Society, including responsibilities held in relation to other groups and organisations. If these changed over time, please detail when and why.

14. Chair

15. As above, I expand on the details of my roles and responsibilities in my answers to the questions below; particularly in this section 3. In this answer to question 5, I

simply outline my roles and responsibilities. This avoids unnecessary and confusing repetition and potential errors of transcription. If the Inquiry wishes, I can provide a reference here to the relevant questions below.

16. Member Resources Committee

17. Member Nominations Committee

18. Member Editorial Committee for 'HQ' magazine

19. Signatory on bank accounts

20. Member Coordination Committee for the UK bid for the WFH World Congress and then of the Organisation Committee for the 2018 World Congress in Glasgow

21. (Probably other minor internal functions I have forgotten.)

22. Separately, for the WFH I was a member of the Structure and Byelaws Committee for their congresses in 2016 and 2018, and the Fund and Resource development committee for the congress in 2018.

23. To the best of my recollection, in relation to my role at the Society I had no responsibilities within any organisation not listed here although I was involved with meetings with many organisations and individuals as part of my role as Chair.

(Q6) When you joined the Haemophilia Society, and throughout your tenure, what were the objectives and functions of the Society? If these changed over time, please detail when and why.

24. "Functions" is not a word I recognise in this context. The aims and objectives of the Society when I joined, as per the Annual report and Accounts to March 2011 (Exhibit WITN3092002), were:

25. (Aims)

    (i) To enable people affected by bleeding disorders to better understand and manage their condition or situation

    (ii) To enable people affected by bleeding disorders to participate in decision making and service delivery

    (iii) To influence policy and improve services

26. (Objectives)

- To provide resources, newsletters and websites
- To provide individual advocacy and support
- To provide opportunities for people with bleeding disorders to meet and support each other
- To campaign on behalf of people affected by bleeding disorders
- To train and support volunteer service user representatives
- To support local groups
- To work with healthcare professionals and other professionals

27. Following a programme of reviewing the Society's strategy, which I initiated at my first board meeting, the Society reworded its aims and objectives into one list of aims, as per the 2013 Annual Report (Exhibit WITN3092004):

- Provide information on all aspects of bleeding disorders
- Advocate with the Government and the Health Service to maintain and improve the standard of treatment
- Encourage patients to take an active role in decisions about their own treatment
- Build networks of community and self help among patients and their families; and
- Advocate for those affected by the use of contaminated blood products by the NHS

28. When Rachel Youngman was interim CEO, we took advantage of her experience to have her review our presentation of these aims. This included reviewing how other charities presented their aims, and again this involved extensive involvement of the trustees and agreement by the board. As per the 2014 Annual Report (Exhibit WITN3092005), the aims were restated in a more modern formulation – without changing the underlying meaning except for the addition of a vision statement - as:

"Our vision: Wellbeing for everyone with a bleeding disorder

Our mission: For all those affected by bleeding disorders, we will provide information and services; build community and mutual support; influence government health and welfare policies, including advocating for those impacted by contaminated blood; and involve people in making decisions about their own care."

29. In the context of the Inquiry, it is worth noting that the Society had similar aims as other patients' charities, but it had an additional area of responsibility to its community as regards the historic (and continuing) legacy of Contaminated Blood. This was reflected in all of the board discussions on strategy, and in each of the different formulations above.

30. Although the formulations changed because of a desire to make the aims fully aligned with our strategy, and to make the language and presentation as readable and attractive as possible, there is complete continuity between the three formulations.

(Q7) Please describe how the organisation was structured, including the governance arrangements and the day to day management and running of the Society. If this changed over the period of your tenure, please set out those changes.

31. The day-to-day management was in the hands of the CEO reporting to the Chair.

32. The Chair reported to the board of trustees.

33. Trustees were elected by the members for 3-year periods, with a minority of trustees being coopted by the board.

34. (Trustees were unpaid, but received expenses, such as travel expenses to board meetings.)

35. The board met some 7 times a year.

36. The CEO was present at board meetings, as at times were some other senior staff members. (Occasionally, for items impacting the CEO or staff they would be excluded.)

37. The board delegated some functions to subcommittees, eg Resources and Nominations. However all material issues were referred back to the board for review and final decisions.

38. The overall governance of the Society was in the hands of a General Meeting of the members. For example, changing the Memorandum & Articles, which defined the governance, required a decision at a General Meeting. There was an Annual General Meeting every year and a process for a sufficient number of members to call a Special General Meeting. (The latter did not happen during my time in office.)

39. My understanding is that this a standard governance structure for charities.

(Q8) Please describe the relationship between the Board of Trustees, Council, Executive Committee and the day-to-day management of the Society

40. There was no Council or Executive Committee during my tenure.

41. The governance of the Society was as per my reply to question 7.

42. There was generally a good relationship between individual staff members and individual trustees, and at any time several of the trustees would have been supporting particular pieces of work within the Society and would have been in contact with the relevant staff member.

43. I would emphasise that such involvement of a trustee was no different from where someone other than a trustee supported a piece of work – the trustee could not give direct instructions to staff members or overrule them.

44. As is normal in a charity, the CEO communicated regularly with the Chair, and the Finance officer communicated regularly with the Treasurer who was a Trustee.

(Q9) What methods, if any, did you use to report the Haemophilia Society's activities to the Executive Committee and/or Board of Trustees?

45. As explained above, there was no Executive Committee.

46. At each board meeting, there were papers distributed in advance on all items to be discussed and/or agreed. My memory is that from after July 2013 this always included a report from the CEO on her activities in the period. Prior to that, Chris James, the then CEO, had (again from my memory) given a verbal update to the board.

47. In addition, the CEO or I would distribute to the trustees between board meetings updates on particularly important items, particularly where these needed their input or approval.

48. As per question 8 above, there was also direct communication between staff members and trustees where they were working together on particular activities.

49. In particular, the Finance officer communicated regularly with the Treasurer who was a Trustee.

(Q10) Please list all the different committees and advisory bodies that you recall were set up within the Society and describe the purpose, functions and responsibilities of each committee or advisory body

50. The subcommittees were:

(a) RESOURCES (To review finance issues and present recommendations to the full board)

(b) NOMINATIONS (to manage recruitment of senior staff and coopted trustees and make recommendations to the full board)

(c) EDITORIAL (To review the content of HQ magazine. This did not report to the board as its function was operational)

I was a member of each of these.

51. The sole advisory body was:

The CLINICAL ADVISORY GROUP

I was not a member of this.

52. This was not a subcommittee but a formally constituted independent group of respected clinicians constituted by the Society and chaired by a Trustee of the Society who was not a clinician.

53. The purpose of the CAG was to provide expert advice on request from the Society, and by exception to offer advice proactively. The board agreed that the Society would ask advice on all clinical matters from the CAG. This included its own publications, lobbying, and policy issues.

54. The creation of this group was agreed at the January 2012 board meeting. It replaced a less formally organised Medical Advisory Committee.

55. It took considerable time to get agreement of the clinicians to join this group and to organise its first formal meeting which was in October 2012.

56. In practice, the group did not often meet formally but Kate Khair for the Society (on whom I give more information in my reply to question 13 below) communicated with its clinical chair Mike Makris, a highly prominent and respected haemophilia doctor. He was then a Reader in Haemophilia and Thrombosis at the University of Sheffield, and the following year became Professor in the same department. Mike would either answer questions himself or liaise with other members of the CAG to get an answer. The membership of the CAG was selected to include respected clinicians in the spectrum of fields most relevant to people with bleeding disorders. This meant not just haemophilia doctors and nurses, but also some dozen or so other specialities including dentistry, hepatology, and physiotherapy.

(Q11) 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

57. I have set this out in my answer to question 10 above as regards the structural subcommittees and the advisory group.

58. The only relevant body not covered under question 10 is the organisation group for the 2018 WFH World Congress in Glasgow. This was a (fairly informal) group chaired by the Society and with representatives from the Society, from the UKHCDO, and the SECC, as well as from some individuals who had been involved locally in Glasgow in the bid process and continued their involvement. The main process for establishing the Congress was managed directly by the WFH, with the Society providing input (and some members of committees). The role of the organisation group was to ensure good communications between all parties locally and between the Society and the SECC, and to make suggestions to the Society board on governance and operational issues.

(Q12) In relation to the committees and advisory bodies that you have addressed above, please detail your role and/or involvement with them

59. I was Chair of the board of trustees.

60. For all other organisational units which I was a member of, I was an ordinary member with the same role as other members. Each of these units had a chair – I was not chair of any of them.

(Q13) Please identify which of these committees and/or advisory bodies, if any, provided medical advice and/or opinions on the safety of blood products and/or the risks of transmission of diseases, including vCJD, to the Haemophilia Society's Executive Committee, Trustees and staff. With regard to these committees, please answer the following:

61. As noted above, there was no Executive Committee.

62. The only body giving advice on clinical matters to the Society was the CAG. This advised the board on request, but in practice the CEO was also able to ask advice directly.

63. Where the Society published any material giving clinical information, this should have been checked with the CAG – and to the best of my knowledge and memory this was always done.

64. The Society board, by convention rather than as a requirement in the Memorandum & Articles, had at least one trustee who was a clinician. In my period this was Kate Khair, a senior Haemophilia nurse (who obtained her PhD during my time at the Society). She reviewed HQ and all booklets which the Society published to check for clinical details. She removed incorrect information or advice, and acted as a gateway to the CAG for checking.

65. The Society clarified in its publications that it was giving general information, not clinical advice. For example, HQ Magazine winter 2010-11 (Exhibit WITN3092008) and subsequent editions state prominently: "The content of HQ is for general information only. If you are experiencing symptoms or you are concerned about any of the issues raised in the magazine we advise that you consult your doctor."

66. In HQ winter 2011(Exhibit WITN3092009) this advice was strengthened to:

"The Haemophilia Society is a patients' organisation which cannot give individual medical advice. All of the Society's publications are for general information only. If you are experiencing symptoms or you are concerned about any of the issues raised in the magazine, we advise that you consult qualified medical advice."

67. In subsequent editions this seems to have reverted to the shorter version above.

68. In researching this statement I have been able to obtain a copy of only one booklet from the period of my tenure, "Understanding Von Willebrand Disease" dated October 2015 (Exhibit WITN3092013). On the back cover this states "The Haemophilia Society makes every effort to make sure that its services provide up-to-date, unbiased and accurate information about bleeding disorders. We hope that this information will add to the medical advice you have received and help you to take part in decisions related to your treatment and care. Please do continue to talk to your doctor or specialist nurse if you are worried about any medical issues.

69. I assume that this message was printed on all of the booklets we produced. However, in any case, I am confident from my memories of discussions at the time and of the attitude of the CEOs and of Kate Khair who were responsible for production and review of these booklets that these were clearly restricted to giving information and not advice.

70. I discuss the contents of this particular booklet in more detail in my response to question 15 below.

a. **Did any clinicians attend any of these committees? If so, please set out how they were selected to join the committee(s).**

71. No external person joined any meetings of the board or committees unless by special invitation which would be minuted. I do not recall any clinicians joining any such meetings in their role as clinicians. I note that GRO-D, a dentist from Glasgow, attended part of a board meeting in connection with our bid for the WFH World Congress – but this was not in his capacity as a clinician.

72. As noted above, one trustee was a clinician.

73. All but one members of the CAG were clinicians. The exception was the chair who was a lay trustee of the Society.

b. **Did any representatives of pharmaceutical organisations attend any of these committees? If so, please set out how they were selected to join the committee(s) and what their role on the committee(s) was.**

74. I do not recall that any representative of a pharmaceutical company joined any board or committee meeting. If they did it would be in the minutes.

75. They would have had meetings with staff members, particularly in connection with activities they might fund or were funding.

76. I am certain that no company representative was involved in any CAG meeting or discussion, since this would have been outside their terms of reference.

c. To what extent, if at all, did the Haemophilia Society rely on findings or conclusions from these Committees to form its policies?

77. All internal committees reported to the board which made overall decisions.

78. The society relied on advice from the CAG on clinical issues. This was in the context of being careful to present the best available information, and also to clarify that this was not advice and that people should seek advice directly from a clinician.

d. To what extent did the Haemophilia Society verify the accuracy of reports and discussion documents produced by these Committees? If so, please provide details.

79. In this context the "Haemophilia Society" is the board, including input from the CEO.

80. We reviewed all documents from internal committees to the extent required by our duties as trustees, and in most cases, given the high motivation and capability of our trustees, beyond.

81. As is usual in governance of well-run organisations, this would generally not go beyond reviewing the internal logic of documents against information already known to trustees or the CEO. Where there were discrepancies, this might have triggered further investigation. I cannot remember specific instances. Also, where there were relevant new clinical issues the board might have referred these to the CAG. This definitely happened with some board papers - for example, we took advice from the CAG on the Contaminated Blood policy [pages 2-4 of **HSOC0029699**]. However, I cannot remember if we ever had to take such advice on a paper from one of the committees.

82. This does not mean that the board automatically accepted recommendations from internal committees. It could accept a discussion document, but decide on a different course of action.

83. As regards the CAG, I am confident that we never sought to go to additional experts for a second opinion.

84. The minutes of these committees should be available from the society if the Inquiry has relevant specific questions.

e. <u>To what extent did the Haemophilia Society rely on its own judgement when deciding whether or not to formulate policy on the basis of the findings or conclusions from these Committees?</u>

85. As explained in d) above.

f. <u>Please give all examples, relevant to the Inquiry's Terms of Reference, of when the Society did not follow the advice from these Committees.</u>

86. By definition, the society followed the "advice" of its board which was responsible for all decisions. As per my answer to d) above, the board may have on occasion not followed the recommendation of one of its Committees. This is normal in the governance of charities. However, I cannot recall any specific examples.

87. If the Inquiry has a specific example it wants to ask about, then I will try to help.

88. As regards the Clinical Advisory Group, I strongly believe that we always did follow their advice.

<u>(Q14) Please explain your working relationship with the Chief Executive in your role in the Haemophilia Society. What was their role in relation to yours? How closely did you work together on decisions? Did this relationship and/ or dynamic change at all following the change in Chief Executive in 2014?</u>

89. I worked closely, constructively, and successfully with each of the three CEOs who were in post during my tenure, Chris James, Rachel Youngman, and Liz Carroll, but there was a very different dynamic in my relationship with each of these.

90. When I was appointed as Chair in November 2011, the context was that the Society had been stressed for many years by the demands of involvement in first the Archer Inquiry and then the Penrose Inquiry. For a small, under-funded organisation, this had made it impossible to deliver effectively in every area of its objectives to support people with bleeding disorders. A major reason that I was appointed as Chair was because of my background in business strategy and implementation of

change, and it was clear that the Board of Trustees expected a review of strategy and implementation of an appropriate balance of services across all of the needs of the community of people with bleeding disorders. My being outside that community was seen as an advantage in letting me approach the situation with new eyes.

91. From my first board meeting as Chair, I drove both a review of strategy and a detailed review of the services which the Society was delivering. When we reviewed the current situation and the structures we needed to have in place to achieve our key priorities, it was apparent that there was a great deal of change to agree and implement.

92. Chris James was CEO when I joined. He was very knowledgeable and had many strengths including building strong personal relationships with members, GRO-D GRO-D. As a result, I became more closely involved with the detail of Chris's work than would be normal for a Chair and a CEO. I also had to coach Chris in some areas of his role.

93. Under my close management, Chris achieved success in many areas, in particular in improving the "central services" of the Society. This included, for example, working with the APPG and professionalising our involvement in the HA meetings with the DoH. The society at this time was less successful in improving "member services" such as revitalising and growing Local Groups and establishing relationships with Haemophilia Centres, although Chris did preliminary work in these areas which bore fruit under his successors.

94. Chris resigned on 1 July 2013. Rachel Youngman joined as an Interim CEO from 30 July 2013 to the end of 2013.

95. Rachel was highly focused and capable, but for cost reasons she worked for us only 3 days a week. As she had to manage significant change within the Society, and as she was always going to be in post for a relatively short time, she recommended that she concentrate on matters internal to the Society and its members, and I took over the relationships with external bodies pending the arrival of a permanent CEO.

96. We worked together in a partnership, as one would expect in a Chair-CEO relationship, with her managing day-to-day items and me providing strategic direction and periodic challenge. Because of the circumstances described above, exchange of information was more detailed and more frequent than would be

normal, but this generally did not involve me giving direct instructions to her. The dynamic was more that we would ask each other's thoughts on specific issues and reach an agreed course of action. She reported formally to me on timings aligned with board meetings.

97. When Liz Carroll joined as CEO on 1 January 2014 she immediately took on all responsibilities for day-to-day management, including managing the relationships with external bodies.

98. Liz and I had a fully conventional Chair-CEO relationship, with her managing day to day and suggesting many of the strategic ideas which eventually became Society policy, and me providing strategic oversight and challenge. We had a close and effective relationship, again probably with more information exchange than might be usual simply because we both felt we worked better that way.

99. Liz remained in post for several years after the end of my tenure as Chair.

SECTION 4: COMMUNICATION AND DISSEMINATION OF INFORMATION BY THE SOCIETY

4.1 PUBLICATIONS

(Q15) Please identify the members of the Executive Committee and/or committees of the Haemophilia Society responsible for editing and selecting material for the Haemophilia Quarterly ("HQ") and other Haemophilia Society publications during your tenure.

100. The publications split into HQ Magazine, booklets giving information, website, and social media.

101. HQ
When I joined there was an editorial committee with Sue Royal and I as trustees and the CEO and Dan Farthing (Communications Officer) as staff members. Dan would propose articles and the editorial committee would review. As noted in a previous answer, Kate Khair as a trustee and clinician would also review to identify any clinical issues.

102. This structure changed after Sue Royal left as a trustee in November 2012. I stayed on as the board member reviewing the newsletter, but after the summer 2013 edition there was less need for extensive hands-on involvement by trustees.

We had a new contractor Chris Keeling-Rowe who took responsibility for production of HQ. She was very capable and professional and resolved the prevailing issues around the production timetable, overall design, quality of presentation, spelling and grammatical errors, and maintaining consistency. We also had a new staff member Nina Benscher who became involved in sourcing articles from members and articles on fundraising, thus improving content. Rachel Youngman and then Liz Carroll replaced Chris James on the editorial committee and Liz in her CEO role took full responsibility for the end-to-end production of HQ with me providing a review. Kate continued her review for clinical issues throughout.

103. Booklets

As for other Society publications, these were produced to give general information and not advice. I was not directly involved with production of these. These were the responsibility of the CEO, with the board I think signing off on which booklets we should produce or update. Kate Khair would review all booklets and check with the CAG as required.

104. In researching this statement I have been able to obtain a copy of only one booklet from the period of my tenure, "Understanding Von Willebrand Disease" dated October 2015 (Exhibit WITN3092013).

105. This explains the biology, symptoms, and treatment for Von Willebrand Disease (VWD). It does not give advice other than for readers to contact a clinician if they believe they may have VWD or need further help and to take the Society's booklet with them as many GPS etc may not be aware of the details of VWD given that it is rare.

106. Thus the booklet says "If you have had a diagnosis of VWD, it's important to speak to your haemophilia centre if you are bleeding. If you aren't sure if you have VWD but have one or more of the symptoms listed below it's important you see your GP. It may be helpful to take this booklet with you."

107. And on the back cover it states "The Haemophilia Society makes every effort to make sure that its services provide up-to-date, unbiased and accurate information about bleeding disorders. We hope that this information will add to the medical advice you have received and help you to take part in decisions related to your treatment and care. Please do continue to talk to your doctor or specialist nurse if you are worried about any medical issues."

108. From my memory of how the CEOs understood their responsibilities and how Kate Khair approached her review role, I am confident that the other booklets produced during my tenure were equally clear in giving only information and not clinical advice.

109. Website and social media

These were much more urgent and less amenable to a structured review process beyond an immediate one-up staff review. Generally there was a more relaxed attitude in content of social media, where there was more expectation of immediacy, possibly with resultant rough edges. I was involved in at least one issue where a member felt that a social media posting was inappropriate, and I had to engage in a correspondence in which I apologised on behalf of the Society. The CEO was responsible for ensuring that the website and social media made clear that any information we gave was not clinical advice (or indeed advice on benefits – another area where the Society had a duty to inform its members).

(Q16) To what extent, if any, did representatives of pharmaceutical companies assist in proposing and/or editing and/or selecting material for the Haemophilia Society's publications?

110. During my period as Chair, I instructed that we should not publish articles directly relating to Pharmaceutical Companies unless there was a genuine clinical interest for our members. (This is not to say that the Society published such articles before my period; I just wanted to make the position absolutely clear.)

111. In the 7 editions of HQ I have been able to find out of the 9 produced in my period, there are no articles directly relating to pharmaceutical companies.

HQ Winter 2010-11	WITN3092008
HQ Winter 11	WITN3092009
HQ Spring 2012	WITN3092010
HQ Winter 2012 – 2013	HSOC0023057
HQ Summer 2013	HSOC0023056
HQ Summer 2014	WITN3092011
HQ Winter 2015	WITN3092012

112. There are articles on clinical trials, independent of any individual company. These encouraged members to consider taking part in trials where they could see the potential benefit for themselves and others, but only to do so where they fully understood and accepted the risks involved. This is discussed in more detail in my answer to question 100 below.

(Q17) How did the Haemophilia Society select or identify contributors and interview subjects for its publications? What were the criteria, if any, for someone to be able to write an article for a publication?

113. At the start of my tenure, Dan Farthing (Communications Officer) would propose articles, presumably in conjunction with Chris James. Other staff members would propose articles related to their responsibilities. Trustees similarly would propose articles. There were standard slots such as the CEO and Chair reports, Contaminated Blood, and Fundraising which would appear in every edition.

114. When Nina Benscher joined as Fundraising and Communications Officer and Dan left, she took over Dan's role on HQ. When Nina left this role was taken on more directly by Liz Carroll, who delegated much of the work to Chris Keeling-Rowe who worked on a contract basis for the Society.

115. The criteria for authorship was having something relevant to say to our members. We were approached by members with proposed articles, and we published many of these (after review and editing).

116. As explained above, review was by the Editorial Committee and by Kate Khair for clinical content. The Committee initially had me and one other trustee, but after she left in late 2012 we did not replace her as I was more up to speed with the issues involved. When Liz Carroll came on board as CEO, she along with Chris Keeling-Rowe took a more hands-on and effective role with HQ and the review process became less important, although Kate and I continued our careful reading and commenting on drafts.

(Q18) Specifically, in relation to its publications which gave medical and/or other similar opinions including those on treatment options:

117. The Society published information on clinical issues, not opinion or advice.

118. As per my reply to question 10 above, we established a CAG in January 2012 to which we referred all clinical issues.

119. The Society published information booklets on various clinical topics relevant to people with bleeding disorders.

a. <u>How were the contributors identified?</u>

120. I am not sure on this, but certainly Kate Khair checked that the main author was appropriate and reviewed the finished booklets. In at least one case we did not publish a booklet because it did not meet our standards.

b. <u>To what extent (if at all) were medical professionals relied upon to produce advice and opinions in publications?</u>

121. As noted repeatedly in my statement, the Society during my tenure (and to my knowledge in the period immediately before) did not publish advice or its own opinions in clinical matters. I believe that it on occasion published opinions from individuals, for example in HQ, but the relevant articles would have pointed out clearly that these did not necessarily represent the view of the Society. However, for the benefit of its members the Society did publish information on clinical matters, which we wished to represent the consensus of the clinical and research communities and to clearly differentiate what was known and accepted practice from what was unknown. This required getting assurance from experts in the appropriate field.

122. When I started as Chair, there was an informal system whereby a group of experienced clinicians "The Clinical Experts Group" were consulted on any relevant statement to be made in a Society publication. It was recognised that this should be done before any publication. There was a clinically qualified trustee who took responsibility for this review and consultation (during my tenure Kate Khair and previously Debra Pollard).

123. We tightened up the process at the 25 January 2012 board meeting by agreeing the formation of a Clinical Advisory Group (CAG) "which shall provide clinical advice on all aspects of treatment relevant to bleeding disorders. The Society shall ensure that all of the Society's statements and publications on clinical issues are evidenced by minutes or written reports of the CAG." (From the board papers and minutes, Exhibits WITN3092014 and WITN3092015) We kept the larger Clinical Experts Group (CEG) in being and indeed added to it from different specialities, and the members of the CAG were automatically members of the CEG. However, the CEG

existed in practice as a list of specialists available to be contacted by the CAG as required – it did not meet as a group or have a specified function.

124. The Clinical Experts Group at the time I joined had been less diverse, being heavily weighted towards the UKHCDO with fewer additional specialities.

c. <u>If medical professionals were relied upon, please provide the names of the medical professionals</u>

125. This would have changed over time but included respected clinicians across some 12 or 15 specialities and in particular members of the UKHCDO and the Haemophilia Nurses' Association. The CAG was about 10 people.

126. The names will be available from the minutes of the Society board and of the CAG, and I think that the members are listed and thanked in the Society's annual reports. However, I cannot evidence names from memory except for the CAG chair Mike Makris as noted above in my answer to question 10.

d. <u>Please set out who decided and how it was decided which medical professionals should be approached for any such advice.</u>

127. The CEO would have been responsible day-to-day to ensure that we took appropriate advice.

128. Generally Kate Khair as our trustee who was also a clinician decided whom on the CAG (or potentially the CEG) to approach. In some cases, the trustee who chaired the CAG may have discussed this with Mike Makris, who was the chief clinician on the CAG.

e. <u>Whose responsibility was it, within the Haemophilia Society, to seek any such advice?</u>

129. I have answered this in under d) above

f. <u>Please set out all examples, relevant to the Inquiry's Terms of Reference, of when the Society provided medical advice and/or opinions in its publications. If advice was received, was that advice edited? If so, why, and by whom, was it edited?</u>

130. As explained many times above, the Society did not give clinical advice or opinions in the period covered by my witness statement.

(Q19) 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 am surprised that the Inquiry has asked this question to me.

132. Chris's remark relates to the early 1980s. I cannot add any information on events which took place over 20 years before I became involved with the Society.

4.2 COMMUNICATION TO MEMBERS

(Q20) How did you interact with members during this time? What were the main concerns and issues reported or relayed to the Haemophilia Society? How did you respond to the concerns?

133. My photograph and Society email address was on the website and was also given in each edition of HQ. This was to enable members to contact me directly if they wished.

134. Unfortunately, the Society at that time apparently erased email accounts soon after the trustee or staff member left, so that I cannot review the emails I received and sent through my Society address.

135. My memory is that I had email correspondence with members on relatively few occasions, but generally in some depth. This generally involved either:

(a) Complaints about board decisions or actions by the CEO or by me, where I needed to defuse a situation, often by explaining the situation from the Society's perspective and asking to agree to differ. Some correspondence on Contaminated Blood came into this category.

(b) Complaints about some lower-level aspect of the Society, where I would research and then either explain why we did what we did or, if necessary, apologise and make a commitment to a change which would prevent the same situation arising in future. (Or at least attempt to)

(c) Requests to help with applications to the Macfarlane, Caxton, or Skipton Trusts. I would generally write to the Trusts on behalf of the applicant, putting their request in context (without stating that I had full proof of the information given) and asking for speedy and specified action. For example, one woman wrote to complain that the Macfarlane trust would not help her pay to repair a roof which was letting the rain in without her providing proof that the roof was leaking and two quotes to fix it. I immediately wrote to the Trust pointing out that this was urgent and suggesting that they had a Skype call with the woman to see the rain and that they paid her for repairs and checked afterwards that the cost was reasonable.

136. I would typically discuss and agree my responses in all these cases with the CEO. As well as cases sourced from members emailing me directly I would also pick up cases where members had complained to staff and the CEO asked me to help defuse the situation.

137. I regularly met members face to face at various events, including local group meetings, fundraising events, and AGMs – and also members who happened to be passing through the Society office at the same time as me, and I spoke with many members over my 4 years. However, as I did not have a bleeding disorder or a direct contact with someone who did, I did not take on a role of deep involvement with the life of the bleeding disorder community that my predecessor and I assume successors did.

138. The only consistent theme I am aware of in members' concerns is about the trusts administering support for those infected or affected by Contaminated Blood. This certainly does not mean that this was a majority of concerns or issues raised – for example there were many individual concerns about treatment in particular places at particular times. But complaints about treatment almost never came directly to me. However, I cannot from memory categorise and quantify all the discussions I had with members or heard about through the staff or other trustees.

(Q21) Did the Haemophilia Society receive direct inquiries from the public or members who required advice with regard to treatment with blood products, such as receiving recombinant 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 in order to respond to these queries and from whom that had been provided.

139. The Society received all sorts of direct enquiries from members or the public, doubtless including requests for medical advice.

140. At the start of my tenure the Society had a helpline. The operator was tasked not to give medical advice or opinion, and either to provide information by reference to our website or by sending a booklet and to recommend that for advice the caller contacted an appropriate doctor or other clinician.

141. When we reviewed this in 2012, we realised that we were not properly managing this service. For example, there was not a detailed log of calls or recordings, and although the staff members involved were experienced and knowledgeable they did not have specialised training. We therefore discontinued the general helpline about (I think) the end of 2012.

142. We maintained a helpline specifically on benefit issues until mid 2013, when the relevant staff member left. My memory is that Liz Carroll then found a service on benefits operated by another charity which we could buy into, although I cannot be sure of this. (If the Inquiry needs this information, it should be available from the board minutes.)

143. The Society would have continued to receive general enquiries to its listed office number. If these were other than extremely straightforward, they would have been routed to the CEO.

(Q22) Please detail any other activities the Haemophilia Society conducted with the purpose of disseminating information to its members during your tenure. If this changed over time please detail when and why

144. The Society disseminated information to its members primarily on its website, and through HQ, through booklets, and through social media, all of which are discussed in my reply to question 15 above. I put a great deal of emphasis from my first board meeting on the need to improve the website, but owing to the poor technical state of the existing site, cost, and other strategic priorities, it took about 3 years to get the site to an acceptable standard.

145. The Society also ran various events which at least in part were to disseminate and share information, for example on women's bleeding disorders or residential

weekends for young boys with haemophilia. Over my tenure (and especially under Liz Carroll as CEO) such events became more frequent as we became better at providing member services.

4.3 HAEMOPHILIA ALLIANCE

(Q23) The Haemophilia Society is a founding member of Haemophilia Alliance which had two meetings each year with the Department of Health, as referred to in [HSOC0023057, page 27]. During your tenure, what items were discussed at these meetings? How were topics decided upon to raise at these meeting? How much did the Haemophilia Society contribute to the list of issues which were sent to the Department of Health? How many of the issues were those raised by members of the Haemophilia Society?

146. I give in the paragraphs below the information which I can remember or source in relation to this question.

147. If the Inquiry wishes to know "what items were discussed" at the 5 or more meetings of the HA of several hours each during my tenure, I recommend that it obtains the minutes of these meetings from the DoH.

148. However, as these minutes were sometimes neither complete nor fully accurate, I would also urge the Inquiry to obtain the papers for these meetings including the "run list" submission from the Society, as this would round out the picture of what was discussed.

149. These meetings were established to fulfil the government's commitment following the Archer Report to create a forum where all issues affecting the bleeding disorder community, including issues relating specifically to those infected and affected by Contaminated Blood, could be discussed between the various stakeholders (including the community itself) and the government.

150. (Note that I do not know whether the HA was a pre-existing structure which was adapted for the purpose explained in the paragraph above, or whether it was specially created at the time that these meetings were established.)

151. The Archer Report specifically talked about medical and support issues and the government accepted the full recommendation. However, the DoH refused to discuss issues other than medical issues at the HA meetings (or indeed face to face or in other forums).

152. In this context, it is important to understand that financial support for the affected community came from the DoH. The DoH established the system of support through the various trusts and schemes, appointed trustees to some or all of these, set the overall rules under which these trusts and schemes gave money to beneficiaries, and funded the trusts and schemes each year out of the DoH budget. Therefore the only government department with any responsibility for support issues was the DoH. Indeed when David Cameron committed to extra funding, this was allocated to come from the DoH budget rather than contingency funds as would have been expected.

153. In this connection, I draw to the Inquiry's attention the convention (as I understand it) that Government departments are not responsible for unbudgeted new costs arising from past events unless the department itself was responsible for these events. The Government had always publicly denied any responsibility for Contaminated Blood, but David Cameron's decision to allocate the costs of this extra funding to the DoH rather than to contingency funds strongly suggests that the Government and DoH privately did recognise the DoH as being responsible. I trust that this Inquiry will investigate in full this question of Government responsibility, and that alongside questioning witnesses and reviewing relevant documents it will analyse relevant evidence given in the Penrose Report as detailed in my answer to question 114 below.

154. Because the DoH was responsible for support, the Society repeatedly requested at the HA meetings, and with the DoH and with various Health Ministers, to extend the scope of the HA meetings or to create a parallel structure in order to fulfil the government's promise to discuss all issues including support. As at my departure in November 2015 we awaited a reply.

155. After the reorganisation of the NHS in England to become NHS England as an Agency, responsibility for day-to-day operational delivery moved away from the DoH. Although technically the government retained the right to intervene in operational matters and from time to time would do so, organisational structures were reformulated so as to be based in NHS England rather than in the DoH. For the Society, the key such organisational structure in NHS England was the CRG for Haemophilia, which defined the level of care and associated organisational capabilities to support people with bleeding disorders.

156. As a result of these changes, the DoH lost direct leverage on decision making in the NHS in England, and over time the HA meetings seemed to degenerate into talking shops. Consequently, the UKHCDO decided that the CRG for Haemophilia was a more appropriate forum for discussing clinical issues, and the HA meetings eventually lost relevance and I think ceased to take place.

157. In the first couple of months of 2012, when I got up to speed with the my role, I set up a process whereby the Society would send a list of issues for HA meetings to the DoH 3 months before the meeting to give them a chance to investigate and respond. GRO-D GRO-D Typical items from this list (in November 2013) were issues concerning:

- The audit of Haemophilia Centres
- The upcoming tender for Factor 8 product, where the Society participated to represent the patient view
- The impact on patients if a Haemophilia Centre did not achieve "foundation status" under the NHS England reorganisation.
- The availability of Factor 8 and Factor 9 in Accident & Emergency units.
- The progress of the Health Minister's promise to produce an analysis of mortality and morbidity in the cohort of people with haemophilia infected (through Contaminated Blood) with Hepatitis C but still in "Stage 1" – ie not showing the symptoms of cirrhosis which would give them a status of "Stage 2".

158. These are referred to in pages 3-4 of **DHNI0000389**.

159. The Society advertised in HQ and through its other channels for members to contribute issues to raise at these meetings. I cannot remember (and probably never knew) exactly how many of these issues were raised by members, but given how many members were knowledgeable about their own treatment it was probably a majority.

(Q24) How did the Department of Health respond to the issues which were raised? Were any assurances made? If so, how was it ensured that these assurances were actioned?

160. Again I refer the Inquiry to the DoH's minutes of these meetings, to be read in conjunction with the papers submitted including the Society's submitted list of issues. (Other stakeholders also submitted issues.)

161. The Society did not take items off its list of issues until they had been resolved, so an analysis of the paper trail would give an indication of the success of any actions. Certainly the issues of core concern to the Society were not always resolved.

162. As a relevant anecdote, in December 2013 I attended a meeting of the DoH's Advisory Committee on Hepatitis to follow up on our issue referred to in question 23 on the mortality and morbidity rate in Hepatitis C "Stage1" among those infected with Contaminated Blood. At this meeting, one of the experts (all Professors and Consultants or both) stood up and asked the DoH chair: "I have been attending these meetings to advise the government for 8 years; can you please tell me which, if any, of the recommendations of this committee the DoH has actioned?" There was no reply. There was also, as at the end of my tenure in November 2015, no analysis from the DoH of mortality and morbidity in Stage 1 in the Contaminated Blood cohort.

163. After the reorganisation of the English NHS in which it became an agency rather than the direct responsibility of Government, it was not clear what – if anything – the responsibility of the DoH or the Minister was for ensuring that operational issues in the NHS were resolved. We wrote to the Minister in October 2012 to ask for clarification on this question, and followed up with the new Minister, Anna Soubry in 2013. Again, as at November 2015 we had received no answer. We did receive a letter from Anna Soubry in August 2013, [**HSOC0011176**] which nicely illustrates the point above. She stated that "Under the new NHS structures, organisations such as NHS England and the NHS Trust Development Authority are not part of Government. They are independent organisations and will need to make their own decisions about whether to attend these meetings". She then gave a contact address for NHS England as a Post Office Box.

164. She was thus abdicating the government's responsibility for maintaining its commitments made at the time the Haemophilia Alliance was set up, a position which is logically, morally, and, I assume, constitutionally indefensible. We continued to press the government to explain how it would fulfil its commitments made at the time of setting up the Haemophilia Alliance – and in particular how it

would resolve issues outstanding where these were in areas delegated to NHS England. However, as I state above, we received no reply.

(Q25) Who did the Haemophilia Alliance meet with at the Department of Health? What format did these meetings take? Were minutes of these meetings recorded?

165. Of course these meetings were minuted – this is part of the discipline of the Civil Service. As above, the minutes will provide a better answer to this question than I can.

166. The senior DoH employee involved was Rowena Jecock, Head of the Blood Policy Unit.

167. Note that we had a recurrent complaint with the DoH that they produced the minutes far too late after each meeting to allow participants usefully to challenge detail. In 2012 and 2013, we corresponded with the DoH to clarify the minutes as necessary, and where we disagreed we included challenges to the minutes in our list of issues.

(Q26) Please also provide detail on the experts who attended these meetings or who were involved in these meetings. How did they assist in these meetings? Who were they, and who were they selected by? [You may wish to refer to *DHNI0000389* to assist you.]

168. Again the Inquiry can answer this question by obtaining and referring to the minutes and papers.

169. Given that the DoH has its own expertise, I have no doubt that the clinical experts whom they selected to attend these meetings were chosen as being genuinely experts, although I personally knew only a small number of them directly or by reputation. The UKHCDO also attended the HA meetings and were again well capable of selecting their own experts.

170. My observation of these meetings (and some other meetings held by the DoH and the NHS which I attended during my tenure) is that they involved far too many people and were unfocused, and did not impose a discipline on action points – that is to say there was no consistent process of documenting the issue and the required resolution, assigning responsibility and delivery date, reviewing progress at each following meeting until full delivery, and escalating as necessary in the event of non-delivery. Thus, despite the genuine expertise gathered (lots of Professors

and Consultants and equally distinguished clinicians of other types) there was not enough useful discussion and insufficient follow-through of decisions.

(Q27) What was the eventual use of the 'Experts report on Hepatitis C' referred to in [*DHNI0000389, page 4*]? Did the Haemophilia Alliance have any influence over its use?

171. This relates to the analysis I discussed in question 23, and I need to explain the context of this before I answer the question.

172. The report we requested was an analysis of mortality and morbidity in the specific cohort of people with haemophilia infected by Contaminated Blood and who (a) had Hepatitis C and (b) were in "Stage 1" as determined by the DoH clinical criteria.

173. We requested this analysis primarily as an evidence base for the support needs of this population. The widespread belief among the community was that the impact of the disease on the Contaminated Blood population was very different from official statistics which reflected studies across the general population infected with Hepatitis C. This was supported by widespread anecdotal evidence and, as our Contaminated Blood Policy (Exhibit WITN3092016) stated, as agreed with the CAG:

> "Medical evidence suggests that those individuals chronically infected with Hepatitis C, but with no visible damage to the liver, can still have chronic symptoms affecting their ability to earn a living and their need for support. The Skipton evaluation and payment regime should reflect this need"

174. There were plausible medical hypotheses that the progress of the disease would be different owing, for example, to the Contaminated Blood cohort typically being infected at an early age, with repeated re-infection, with multiple strains of the virus including genotypes which were rare in the UK but common abroad where blood products were sourced, and with a higher viral load. Also, of course, there was the unknown impact of the cohort also having haemophilia.

175. In addition, there was an underlying clinical issue that the diagnosis of "Stage 2" required identification of cirrhosis of the liver. This was not a trivial matter, as it involved a relatively inaccurate ultrasound investigation of the liver, or, for a definitive diagnosis, a liver biopsy which could be risky for people with haemophilia (and still far from 100% accurate). It is plausible that this risk made patients and clinicians delay biopsies, resulting in later diagnosis of cirrhosis among the Contaminated Blood cohort than in general cohorts of people with Hepatitis C. In

any case, it is likely that at any time there were many people diagnosed as "Stage 1" who in reality were in "Stage 2".

176. In contrast, the low level of support given by the government through the Skipton fund evidenced that it saw "Stage 1" as a relatively trivial condition not creating serious needs.

177. The Experts Report referred to in this questions was a review of published articles on general cohorts of people with Hepatitis C. It did not include the new analysis we had requested on mortality and morbidity among the specific cohort of people with haemophilia who had contracted Hepatitis C from Contaminated Blood. For example, the information we requested would have included mortality statistics for those in "Stage 1" and those in "Stage 2", with analysis to identify how long those dying in "Stage 2" had been identified as being "Stage 2". This information should have been directly accessible through analysis of Skipton Trust and NHS records.

178. Therefore, the Experts Report did not provide evidence for the specific Contaminated Blood cohort as we had requested. From memory, the Minister had the Experts Report updated to cover articles published from about 2009 to about 2012, but these articles still looked only at the general population and therefore in no way addressed our requirement.

179. The DoH used the Experts Report to argue that there was no evidence of the excess morbidity and mortality in the Contaminated Blood "stage 1" cohort. This was a disingenuous and unscientific use of the data, since as explained above the general populations covered in the Report and the specific Contaminated Blood cohort could be expected to have very different outcomes. The Society criticised this use of the Report and continued to demand production of the specific longitudinal analysis we had requested. (This remained prominent in the Society's Contaminated Blood Policy and in our advocacy through the APPG and elsewhere. See for example my answer to question 31 below.)

180. I am not a clinician, but I assume that had the DoH produced the relevant statistics we requested this would also have informed treatment. It could have been important, for example, for determining the type and frequency of tests to be done for each patient. Because this information was not available, the Contaminated Blood "Stage 1" Hepatitis C patients presumably received suboptimal treatment,

possibly leading to further avoidable deaths alongside an avoidable heavier burden of illness.

181. As noted elsewhere in my answers, the analysis we requested had not been produced as at the end of my tenure in November 2015.

(Q28) Please detail the process of raising issues that did not fall under the Terms of Reference. How did the Secretary of State respond to these issues? Was any practical action enacted as a result? [You may wish to refer to *HSOC0023057, page 26* to assist you.]

182. The main area here was financial and other support and the way in which this was delivered.

183. The Society wrote at various times to specific health ministers and also to the Secretary of State for Health. For example, HQ for winter 2012/13 page 27 (Inquiry document **HSOC0023057**) notes that the society had written to the Secretary of State to request that the terms of reference for the HA meetings with the DoH should be expanded to include issues on access to support from the Skipton Fund and Caxton Foundation.

184. To the best of my memory, the Secretary of State did not respond to the above request or indeed any other, and certainly no relevant practical actions were enacted.

185. The Society kept on lobbying, including through the APPG.

186. As explained in my reply to question 23 above, the DoH was responsible for support, so there was no other route for us to follow. Eventually Alistair Burt with help from the APPG got his commitment from the Prime Minister regarding increased support. I do not know how this affected the Society's interaction with the DoH after my tenure.

SECTION 5: RELATIONSHIP WITH THE GOVERNMENT

(Q29) 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?

187. This question appears to be based on a misapprehension.

188. The Society had no official relationship with the government or individuals in public office.

189. We did have the structure of the HA through which we came into regular contact with middling-level officials of the DoH. These meetings are described in my replies above from question 23 onwards.

190. As is natural, a working relationship developed between each of our successive CEOs and the officials of the DoH he/she came in contact with, notably Rowena Jecock and Ben Cole. My perception is that this helped overcome some potential bureaucratic inertia from the DoH but did not materially improve eventual outcomes. There were certainly occasional meetings between the CEOs and Rowena, but I do not think these were "regular".

(Q30) Please describe the extent of your role and involvement with regard to the Society's interactions with and representations to the Government.

191. I take this question to refer specifically to approaches to Government ministers and not to the Society's general lobbying activities.

192. The board oversaw the Society's approaches to ministers, although this was informed by the recommendation of the CEO.

193. To my memory all letters to ministers were signed by the CEO. With Chris James and Rachel Youngman I would have agreed the exact wording of such letters; with Liz Carroll I agreed the exact wording on some letters but it is possible that we may have sometimes agreed only on the general content.

194. The CEO would have shared any letters from ministers with me immediately and we would have discussed them in detail and agreed on our next action. We would have reported this back to the board.

195. As per the answer to question 31 below, in my 4 years, I had one meeting with a minister, which was an informal meeting with Earl Howe who was a junior minister in the House of Lords.

(Q31) If you attended any meetings, please provide a detailed account of those meetings with Government ministers and/or civil servants and/or other representatives of the Government

196. I interpret this question to exclude large-scale meetings such as the HA and the Advisory Committee on Hepatitis.

197. I have a vague memory of visiting Rowena Jecock at the DoH with Chris James near the start of my tenure to be introduced as the new Chair. I do not think that this meeting (if it indeed happened) would have gone beyond exchanging basic practical information and Rowena trying to explain gently to me the "facts of life" from the DoH perspective.

198. Apart from this I do not recall meeting civil servants, and certainly I did not meet any senior officials. I had one meeting with a junior minister, which I describe in my reply to question 31 below.

199. I did on one occasion visit the MHRA (Medicines and Healthcare products Regulatory Agency). I understand that this is a government agency, so that the senior staff member I met (whose name I do not remember) was presumably not a civil servant but was in some sense "a representative of the Government"

200. This was a meeting to follow up on a request from a Society member concerning a recall request by a foreign manufacturer for a faulty batch of one of the types of blood products used in the UK (although in this case none of the faulty product was in fact delivered to the UK). I went to see the MHRA to get a technical understanding of the process by which they followed up on manufacturers' product/drug recalls, so that if we pursued the member's issue we would be doing so with the correct facts. The meeting was purely for me to receive technical information. I had a subsequent correspondence with the MHRA regarding the metrics they maintained to check the efficiency of their processes. My memory is that I reported back to the member with all the information I had gathered, which I believed was satisfactory in context, and that this resolved the issue for him.

201. In my 4 years I had only one meeting with a minister, so it is worthwhile giving full details:

202. When Baroness Meacher became President of the Society, she arranged an informal meeting for me with Earl Howe who was a junior Health Minister. This was

in the period after Alistair Burt had succeeded in engaging David Cameron on Contaminated Blood. The meeting was on 19 November 2013, and my draft of the minute I sent to Earl Howe afterwards (Exhibit WITN3092017) is:

"Earl Howe,

Thank you for meeting with Baroness Meacher and me yesterday. As the government considers how to set up its process to fulfil the Prime Minister's commitments on contaminated blood, I hope that our contribution provided useful background and insight.

This note is offered as an aide memoire of the central points we raised.

We strongly believe that the key to a successful outcome is for the government to find a way to communicate directly with as many of those affected as possible throughout the process. We do not underestimate the difficulty of this, but effective consultation is an essential ingredient to enable "closure" to be accepted by a majority of the population.

The Prime Minister made commitments in three areas:

- The structure of the trusts used to distribute support
- The sufficiency of support
- Investigating how the original tragedy happened.

On structure, we would see the central issue as establishing a mechanism to understand the opinions of all beneficiaries. This would give evidence for redesign of the structure, and would let you test that a redesigned structure was working. Given the history of poor relations between the trusts and beneficiaries, this consultation should be run by an independent organisation. There would need to be a budget allocated for this.

To establish an appropriate level of support, there should be an analysis of need of the different classes of infected people. It should be noted that there does not seem to be an evidence base to justify using the presence of cirrhosis ("Stage 2") as the sole criterion for differentiating need among those mono-infected with Hepatitis C. We would anticipate that an equitable system would need to involve a greater number of "buckets" of those infected. We

noted that the Expert Group on Hepatitis C is reviewing the possibility of establishing an analysis of the history of mortality and morbidity among the infected cohort; this could inform an analysis of need and also enable an actuarial projection of costs of support.

The Prime Minister's commitment on investigation of "what happened" should be considered in the light of the Archer Inquiry and the Penrose Inquiry report due next March. If the government is willing to have an independent judge-led review taking these inquiries as a starting point, with a limited analysis of additional evidence, it may be possible to reach a report acceptable to all parties within a reasonable time and cost budget. The position is complicated by the fact that we do not know what Lord Penrose will say – conceivably he could reach conclusions unacceptable to the UK Government.

My personal belief is that although there is, understandably, a great deal of bitterness and mistrust among those infected, generosity of engagement by the government on these matters would go a long way to allow achieving "closure" within the constraint of limited resources.

The Haemophilia Society will be pleased to provide ministers and civil servants all the support which it can to help advance the process the government has committed to. Please do contact me if we can assist.

Best regards,

Bernard Manson

Chair, The Haemophilia Society

203. At the meeting I also explained the role of the Society as a patients' charity in securing good care for its members through the NHS, and I would have highlighted major current issues, but I cannot remember the detail of this.

204. If the Inquiry wishes to cross-check, then there should be a minute of this conversation taken by one of the several civil service minders who attended.

In particular please set out the following:

a. When, and, how often did such meetings take place?

205. Answered above in the body of my reply to this question 31.

b. **Who did you meet with?**

206. As in a) above

c. **Were minutes of the meetings recorded, and if so by whom?**

207. My understanding is that all meetings held by ministers are in the presence of civil servants who take minutes. I take it that the Inquiry can check this point and obtain any such minutes it requires from the civil service. As above, there were certainly civil servants present at my meeting with Earl Howe and they took notes.

d. **What were the purposes of the meetings?**

208. As in a) above

e. **What was discussed at the meetings?**

209. As in a) above

f. **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.**

210. No such assurances were given by the Government to the Society.

g. **What decisions and actions were taken by the Society based on information provided by the Government during your tenure? If this changed over time, please detail when and why.**

211. I take it that this question relates to private meetings and communications between Government ministers and the CEO or me. If it relates to the general meetings such as the HA then the answers are elsewhere in my statement, mainly in my responses to Section 4.3. If it relates literally to all information, then I can only answer that doubtless the Society adjusted its HR policies and fire safety procedures and so forth.

212. Where we had communications from ministers then

(a) If these were positive – as with the commitment to investigate Hepatitis C "stage 1" mortality and morbidity – we followed through as best we could

(b) If these were negative then we adjusted our lobbying or advocacy to try to obtain the same result through a different route, for example working with the APPG

h. <u>Did the Haemophilia Society rely on assurances by the Government or individuals in public office on treatment or the risks of vCJD? If so, please provide details, identifying how the Society's approach changed because of those assurances.</u>

213. My strong memory is that in my tenure, the Society consistently requested continued research and vigilance regarding treatments and vCJD, particularly through the HA meetings but also as an issue communicated to the APPG and perhaps through other routes. I do not recall that the government or persons in public office made assurances that such and such was risk free. We would have referred any such statement to our CAG, but I cannot see that they would have agreed that any clinical intervention was risk free or that we would have accepted such an assurance.

214. One issue was that a large number of people with haemophilia had been put on an "at risk" register for vCJD and then were suddenly taken off with little or no explanation some time in 2012. We pursued this with the DoH through the HA meetings to try to get clarity on the reasons why these people were now considered not to be at risk, (This is noted in HQ for winter 2012/13 page 27, Inquiry document **HSOC0023057**). I do not recall that we obtained any assurances on this from the DoH, and there was no satisfactory resolution that I can remember.

215. The CAG in October 2012 queried the use of Cryoprecipitate. This was apparently used for patients with "reduced fibrinogen". The issue was the possibility of vCJD from the UK donors' blood used to produce the Cryoprecipitate and the fact that there was a safer alternative. A medical group with which one of the CAG members was associated had raised this with a committee of the DoH over the preceding three years, but had received no satisfactory reply. The CAG suggested we raise this issue through the HA meetings. I assume we did but I have no clear memory – if the Inquiry is interested the facts should be in the HA papers and minutes.

5.1 ALL PARTY PARLIAMENTARY GROUP

<u>(Q32) In 2012, the All Party Parliamentary Group on Haemophilia and Contaminated Blood ("APPG") was re-established [HSOC0023058, *page 4*]. Please explain what the</u>

goals and priorities of the group were. How, if at all, did this differ from the initial establishment of this Group?

a. How were the goals set?

216. The goals of the current APPG (as at December 2020 from a parliamentary website) are "To promote awareness of, and campaign for, people with haemophilia and other bleeding disorders and people infected with blood-borne viruses due to contaminated blood and blood products used in their healthcare treatment." From memory, the goals were in practice very similar in 2012.

217. My understanding is that the MPs involved in 2012 and before then had become interested in the scandal of Contaminated Blood through approaches by infected and affected constituents. Given that the number of infected people was a multiple of the number of constituencies and that the support given by the government over decades was inadequate or worse, I suspect that most MPs would have had such approaches. I take it that this would have led to the original establishment of the APPG (before the period of my tenure), possibly with advocacy at the time from the Society and from campaign groups, and possibly with the particular initiative of interested parliamentarians such as Lord Morris and Frank Fields. If the Inquiry is interested in this history, I suggest it reviews the parliamentary records.

218. I have no direct knowledge of the goals of the APPG in parliaments before 2012, but my understanding is that they were effectively the same.

b. To what extent, if any, did the APPG achieve these goals during your tenure?

219. The APPG kept Contaminated Blood as a live issue in parliament and provided a framework for action when the political climate enabled it – ie when David Cameron was willing to engage in dialogue on the subject with Alistair Burt.

220. Given the limited power of backbench MPs in our parliamentary system, I think that this represents a huge success, and is a credit to the many MPs who gave of their time and energy to support the APPG over the years.

221. The APPG also provided a conduit for raising issues about current treatment.

c. Why was it decided to be re-established at that point in time?

222. All APPGs are automatically dissolved at an election and therefore the APPG would have been dissolved in May 2010. I do not know why it was not reconstituted immediately after that election, but I when I joined the Society as Chair the process of reconstituting the APPG was already under way. For practical reasons it took until October 2012 to have its first meeting.

d. <u>What was the level of involvement of the Haemophilia Society in the APPG?</u>

223. The Society provided the Secretariat for the APPG.

224. We encouraged out members to ask their MPs to join the APPG.

225. We also did some research and communicated to our members to request support for particular initiatives of the APPG.

226. I think it is fair to say that we saw the APPG as the best route for advocating on Contaminated Blood and as an important channel for issues affecting treatment and safety for patients, and we put a great deal of effort into supporting and maintaining our relationship with the APPG.

<u>(Q33) Who was in the APPG and how were they selected? Please explain what the Group discussed and achieved during the course of your tenure at the Society.</u>

227. The APPG was open to any backbench MP or peer.

228. The members were self-selected MPs and peers.

229. Membership varied over the years, and if the Inquiry wishes it can track this through parliamentary records.

230. The APPG held various private meetings, and also a number of public events in parliament, for example where it gave people infected or affected by Contaminated Blood the chance to state their story.

231. For example, on 8 April 2014 it held public consultation meeting on Contaminated Blood, which I attended. My minute of this (Exhibit WITN3092018), which I sent to the trustees, states in part.

> 'At Alistair Burt's invitation some 20 people present who had been impacted by contaminated blood then spoke individually, giving a brief description of

their situation and making particular points about their experience, needs, and wishes.

It very powerful to hear the same underlying evidence from so many different people in such a dignified way. These were not just the well-known campaigners, although the themes were very consistent. There was a strong anger against the behaviour of the trusts towards their beneficiaries; both the lack of respect and the lack of willingness to take the side of the beneficiaries against the Department of Health. (As a typical example, the lady next to me reported she had been told by a member of staff of Skipton that "she was lucky to be receiving funds from Skipton".)'

232. Also, in 2014 the APPG conducted a structured Inquiry into the Macfarlane, Skipton, and other trusts. This involved developing an evidence base by sending a questionnaire to all beneficiaries to determine their experience of and attitude towards these trusts. The Society provided extensive support for this inquiry, which was published in January 2015 (Exhibits WITN3092019 and WITN3092020, comprising the executive summary and full report). I refer to the report of this inquiry in my answers to questions 71 and 72 below and elsewhere as the "APPG Report".

233. As above, the APPG had little direct power, as it consisted of backbenchers set against the government, but it achieved its core goal of keeping the issues alive, and it was able to provide the framework to support Alistair Burt's initiative – with a direct line of causality to the creation of the current Infected Blood Inquiry.

(Q34) Please outline the role and the responsibilities of the Chair of the APPG. Please identify any other key individuals in the APPG who held roles and outline what those roles involved and the responsibilities they had. Do you consider those roles to have been performed satisfactorily?

234. I cannot give reliable evidence on this as my involvement with the running of the APPG was very peripheral. The Society acted as Secretariat for the APPG, but this was carried out by the CEO and seemed to be related more to helping resolve statutory requirements than with the day-to-day activities of the APPG.

235. The roles and responsibilities of the APPG are a matter of public record. My impression was that the Chairs predominantly did the organisational work of the APPG.

236. I did not have the detailed knowledge to form an opinion on how well the Chairs of the APPG performed their roles. I am aware that the APPG carried out a series of well-organised meetings and events, and of the successful outcomes due to the APPG as per my answer to question 33.

237. I was and am grateful to Diana Johnson and Jason McCartney, who were the Chairs during my tenure, for finding the time during their pressurised lives as MPs to devote to the APPG.

238. I note that as at December 2020, Diana is still a Chair of the APPG and Jason is still a member, demonstrating the longevity of their commitment.

(Q35) How often did the group meet? What constituted a legitimate meeting of the APPG and what constituted an 'illegitimate' meeting of the APPG? What were the consequences of a decision made at an 'illegitimate' meeting, as referred to in [*HSOC0015218*]?

239. From memory the APPG met 2 or 3 times a year, plus it held public events.

240. I am not an expert on parliamentary procedure, and if the Inquiry wants a definitive answer to these questions I suggest it consults the official parliamentary records.

241. I assume than an "illegitimate" meeting is a legal nullity and any decisions or actions taken there have no legal effect.

(Q36) To what extent, if any, was the position of the APPG informed by the views of the Society's membership? Did the views of the APPG differ from the views of the Haemophilia Society Executive Committee, as you understood them?

242. The Society did not have an Executive Committee during my tenure, so I am interpreting the question as if it says "Haemophilia Society's Board".

243. I do not know what the views of the members of the APPG were and presumably they differed one from another.

244. Opinions also varied among member of the Society.

245. As I explain in my reply to question 32 above, many of the MPs in the APPG would have been in contact with one or more constituents who were impacted by Contaminated Blood. Presumably the constituents influenced the MPs, and

presumably most but not all these constituents would have been members of the Society.

246. The Society communicated its policy on Contaminated Blood and other issues to the APPG, and there would have been discussions at various times between the APPG Chairs and the CEO (and occasionally me) as to priorities and tactics. I cannot at this remove remember or comment on details. We shared common goals and my memory is that our discussions were harmonious and effective. Doubtless there were from time to time minor differences.

(Q37) Please explain the level of involvement the Haemophilia Society had in the 'Inquiry into the current support for those affected by the contaminated blood scandal in the UK' [*RLIT0000031*] by the APPG. Did the Haemophilia Society provide any resources to aid the production of the report? Did the APPG produce any other reports during your tenure?

247. The Society worked closely with the APPG on this report. As the report states in its acknowledgements: "The Inquiry has been conducted, and this report produced, in association with The Haemophilia Society".

248. I was not directly involved; Liz Carroll did a lot of work.to support the design, research, and analysis, although the actual questionnaires were sent out by and analysed by an independent research company.

249. I do not recall the APPG producing other reports in my tenure other than minutes of public events it held, but the Inquiry can check this with the parliamentary records.

(Q38) Please detail your relationship with Diana Johnson and Jason McCartney. Did you consider Diana Johnson and Jason McCartney to be satisfactory chairs of and representatives for the APPG? Did they succeed in achieving the aims of the APPG? Do you believe that they could have operated differently in certain aspects and, if so, how? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

250. During my tenure, the CEO had the direct relationship with the APPG and its Chairs, except when Rachel Youngman was interim CEO and I managed external relationships. I attended one or two meetings with Diana Johnson and Jason McCartney.

251. As per my answer to question 32 I am not in a position to comment in detail on the performance of Diana and Jason as APPG Chairs or in alternatives actions they might have pursued. At the time I was hugely impressed by their commitment and activities, and more than satisfied in the way in which they interacted with the Society (and with me personally).

252. I was, and am, grateful for the work that Diana and Jason did for those impacted by Contaminated Blood (and for current treatment in the NHS) alongside their myriad other responsibilities as MPs.

253. I am sure that with the benefit of hindsight everyone (including me) "could have operated differently in certain aspects". In this case, I have no opinion as to "how".

(Q39) In an email from yourself to Christopher James [HSOC0015218], you mention that Lord Morris objected to Jason McCartney's role in the APPG as he believed that Jason McCartney intended to "neuter *the APPG so that it does not trouble the government*". Why did Lord Morris have such a concern? What actions of Jason McCartney had led to this belief? Did you agree with Lord Morris and, if so, why? If you did not agree with him, why did you not? Do you consider that the APPG was effective?

254. I do not know why Lord Morris had a concern about Jason McCartney, nor am I aware of any actions by Jason which might have led to such a belief.

255. I did not agree with Lord Morris, as he offered no evidence for his assertion. My opinion on the subject was not relevant to the conversation.

256. My personal experience of Jason and the reports from our CEOs in the context of APPG business were only positive.

257. I have already answered positively more than once about the effectiveness of the APPG.

258. In case the rather negative reference to Lord Morris in this reply gives the wrong impression, I would like to emphasise that having the privilege to meet him was one of the highlights of my term as Chair of the Society. Through creating the Disabled Persons Act he became one of the few post-war British politicians who achieved positive change with a global impact, and his work for Contaminated Blood was only one part of his lifelong commitment to help the disadvantaged.

(Q40) How often were the members of the Haemophilia Society asked to support the activities of the APPG? Were the members asked to write to their MPs to increase numbers at the AGM so that it would increase the likelihood of Jason McCartney being removed from his role?

259. The Society periodically encouraged its members (for example at AGMs and in HQ) to ask their MP to join the APPG. This was to strengthen the APPG (and at the start of my tenure to ensure that it had enough members to be registered as an APPG).

260. There was no discussion in the Society about replacing Jason McCartney as an APPG Chair, nor was there any attempt by us to suggest or facilitate this.

5.2 POLICY ON CONTAMINATED BLOOD

(Q41) Please set out the relationship between the Haemophilia Society and:

a. The Manor House Group;

b. Tainted Blood;

c. Any other campaigning groups, please provide names of such additional groups.

[You may wish to refer to *HSOC0010542* to assist you.]

261. This question cannot be understood without considerable background information.

262. In the area of Contaminated Blood, there were various campaign groups and also prominent individual campaigners who did not belong to a group. This reflected over 30 years in which the government policy on supporting people infected and affected in different ways had developed piecemeal, with no attempt to evaluate needs systematically and with no attempt to ensure that everyone was treated fairly. There was also a split between those infected though haemophilia product and those infected through whole blood transfusions.

263. As a result, different groups and individuals had different priorities for improvements in the system of support, and there was no consistent set of demands from the community to the government.

264. The Society had historically been in contact informally with the Manor House Group and Tainted Blood, which were the most active campaign groups within the haemophilia community, and also with individual campaigners. In 2012, the Contaminated Blood Group was relatively recently formed (I don't know exactly when), and differed in that it also represented those infected or affected by "whole blood" infections.

265. Each campaign group or individual had a single purpose, whereas the Society had broadly two very different purposes (i) to be a conventional patients' charity for people with haemophilia and other bleeding disorders alongside (ii) supporting those impacted by Contaminated Blood.

266. Given that the Society and the groups had goals for campaigning/advocacy on Contaminated Blood which were conflicting in detail but broadly aligned overall, I decided that

(a) The Society needed to define its policy on Contaminated Blood, in part so that the campaigners could see what we stood for and could decide how to cooperate with us (although we primarily needed a policy to focus our own activities and to let us communicate clearly with our own members, the government, the APPG, and others);

(b) We needed a semi-formal structure for relating to all the groups, where we could maintain good relationships, exchange information, and either agree or agree to disagree, and we could coordinate our approach to the APPG so that we presented a united front to our main channel for influencing government.

267. We had a meeting in April 2012 with Tainted Blood and Manor House as the first step to setting up such a semi-formal structure. We subsequently had a similar meeting with the Contaminated Blood Group. We would also have been in touch with individual campaigners, but I cannot remember names or details at this distance.

268. As per the question, we gave the groups the opportunity to comment on our draft policy so that if possible we could align it more closely with their positions. In general we were able to find common ground, although the Contaminated Blood Group in particular felt that our eventual policy document did not go far enough to emphasise the issues they focused on. At no time did we ask the groups to endorse

our policy – the goal was to be able to work with them even if we had different emphases.

(Q42) Did the Society help to promote the aims and objectives of other similar organisations?

269. We worked with other organisations where we perceived that cooperation would help us to promote our own aims. It was irrelevant to us if these organisations were "similar" to the Society. This was the rationale of our working with the EHC, the APPG, campaign groups, and indeed the DoH and so on.

270. Our duty as charity trustees was to progress the aims of our own charity. We were pleased to give support to other organisations where their aims were closely aligned with ours or where we were sympathetic and there was no major cost or risk to us. However, we took care not to support activities which were counter to our objectives or which we believed would damage the reputation of the Society if we were associated with them.

271. Through our membership of the WFH and the EHC we supported national organisations working in different countries with broadly the same aims as the Society in each of these countries. These national organisations would have been "similar" to the Society. Also although the WFH and EHC were very different from the Society they had aims which overlapped strongly with ours, for example in the area of improving treatment. During my tenure we were not able to devote much time or resource to supporting the activities of the WFH or EHC (except for working towards the 2018 WFH World Congress) but there was certainly an aspiration to become more actively involved.

272. In the UK there were no other organisations with broadly similar aims to the Society, until the formation of the independent Haemophilia Scotland charity. We then cooperated with them, but we did not work "to promote [their] aims and objectives" except insofar as these were completely aligned with ours.

273. I assume that most charities or similar organisations – or indeed the government - cooperate with other organisations in a similar way as a means to promote their own aims and objectives.

(Q43) Did the Society speak out against the aims and objectives of other similar organisations?

274. As explained in my answer to question 43, the only "similar" organisations were other national patients' charities for people with bleeding disorders (and to some extent Haemophilia Scotland). We certainly did not "speak out against" the aims and objectives of any of these organisations.

(Q44) Was there any overlap between those holding roles within the Haemophilia Society, and those holding roles within other similar organisations?

275. As explain in my answer to question 42 the phrase "similar organisations" would mean only other national patients' charities for people with bleeding disorders.

276. I assume that the actual issue of interest for the Inquiry here is where Society trustees were also trustees of the Macfarlane Trust or active in campaign groups. I am answering this question on the assumption that it reads "holding roles within the Macfarlane Trust or any of the campaign groups".

277. (From time to time trustees were also active in the WFH or EHC, but I do not think this created any potential conflicts of interest.)

278. During my tenure we had (I think) one trustee who was active in Manor House and one active in Tainted Blood. (Again from memory, this was not for the full 4 years.) As we maintained generally good relationships with these groups, this did not cause major difficulties. When we discussed our policy on Contaminated Blood, we did not regard the dual membership as creating a conflict of interest. However, because the DoH set arbitrary rules for support and rationed overall funding, there was a conflict of interest between, say, someone who was co-infected with HIV and Hepatitis C and someone who "only" had Hepatitis, or someone who had "stage 1" Hepatitis and someone who had "stage 2" Hepatitis. The trustees were aware of these issues, and we managed the discussions openly and I think successfully.

279. We also had at any time a trustee who was at the same time a trustee of Macfarlane. This was more delicate, as the Society was highly critical of Macfarlane on many counts, but we felt it important that we help it get high-quality trustees who could represent the community's lived experience. (Both from our trustees and from our other members.) This caused difficulties, as tensions ran high amongst Macfarlane beneficiaries and at some times some of our members would accuse our trustees of not standing up for their interests.

280. In the role of Macfarlane trustee, our trustee had to maintain confidentiality and to act only for the benefit of Macfarlane beneficiaries. Ie they could not report to us or take instructions. I think it was appropriate for us to maintain this structure, since the alternative was to allow Macfarlane to choose trustees who were pliable to the wishes of the Macfarlane board, which, by many accounts was dominated by its Chair.

(Q45) What motivated the decision to create a policy on contaminated blood? What was the intended purpose of the document? How was this purpose decided? Do you consider that the policy achieved its intended aim?

281. The "policy on contaminated blood" referred to here is pages 2 to 4 of document **HSOC0029699**.

282. When I became Chair, the only documented definition of the Society's policy on contaminated blood was one of its aims within its overall vision, values, aims, and objectives:

> "To campaign on behalf of people affected by bleeding disorders".

(As discussed in my reply to question 6 above and as in Exhibit WITN3092002)

283. This seemed too vague as a source for engagement with our members and the government in this area, or for briefing the APPG or the press, etc. Also, we needed to define our priorities between Contaminated Blood and our other objectives as a conventional patients' charity.

284. This led to two initiatives from the first board meeting I chaired in November 2011: (i) revising our strategy (which would include revising our vision, aims, and objectives) and (ii) agreeing a policy on Contaminated Blood [**HSOC0029699**]. (I discuss the revision of strategy in my reply to question 6 above.)

285. (A further impetus for the strategy revision was a perception that we were not delivering services which were relevant to all groups with bleeding disorders.)

286. It is worthwhile adding an extract from an email I wrote on 5 June 2012 to one of the trustees (Exhibit WITN3092021) regarding the development of the Contaminated Blood Policy:

"To explain my position on this, unless we have a written statement of policy I do not think we can engage coherently in public debate and push government to move. I believe that the history of the Society's engagement with this subject, and the historic bad opinion of the Society held by some of those directly affected by contaminated blood, supports my view, I am doing my best to ensure that the eventual policy document represents a broadly acceptable view - as is the nature of these things no one is going to be 100% satisfied with any formulation."

287. The purpose was agreed by the Board of trustees after an extended period of review and obtaining comments from members and others. As well as simply defining a policy, we wanted a policy which was (a) acceptable to (ideally) the vast majority of members as adequately representing their views (b) seen by the Board as an appropriate basis for advocacy with the government and (c) seen by the Board as a starting point for our response to the Penrose Report. We saw the campaign groups as additional stakeholders whom we wanted to be able to support the policy as a policy for the Society, even if they did not agree with particular aspects which might differ from their own policies.

288. I believe that the policy achieved its central aims, viz:

- It was accepted by the vast majority of the members
- It was seen by the Board as an effective basis for advocacy and as a starting point for a response to Penrose
- The campaign groups were able to continue to work with us.
- It gave more clarity to the APPG in its cooperation with the Society, and highlighted particular issues which the Society saw as priorities.
- It provided a briefing document to give to the press, etc.

(Q46) How were policy topics decided on for inclusion in the final document? Did the members of the Haemophilia Society help to contribute to the selection of topics? Please detail as many of these topics as possible.

289. The "policy on contaminated blood" referred to here is pages 2 to 4 of document **HSOC0029699**.

290. The policy was discussed at length at successive board meetings from January to September 2012. It was also discussed with campaign groups in April and May 2012, and in summer 2012 we discussed it with HS (at that time a group within the Society) and published a draft on our website asking for comments from members. At the same time we circulated our list of people we knew were involved in Contaminated Blood. We received 32 comments from individual members, and considered each of these at the board.

291. Broadly the campaign groups accepted the policy with some of the changes which they requested accepted by us in full or in part, and the wording adjusted accordingly. I am sure they retained reservations on particular points, particularly the Contaminated Blood Group as noted in my reply to question 41.

292. The only group not to accept the policy was HS, which objected to the statement that there should be a Public Inquiry. They stated that their experience with Penrose gave them a unique insight in this area, and that a UK Inquiry would be bad for the (non-Scottish) community. Given that none of the 91% of our members outside Scotland requested that we remove the demand for an Inquiry, we were confident that it was correct to keep the demand in the policy. (We also suspected that HS's position was influenced more by internal Scottish politics than by any belief in the effect of a UK Inquiry.)

293. It is worth adding, that although the Society had little positive power, if we had not called for a UK Public Inquiry, the government would undoubtedly have used this as a reason not to hold such an Inquiry on the grounds that "the community involved does not want it".

294. After we agreed the policy in September 2012, we were approached by HS with an opinion from a respected Scottish firm of solicitors that the wording of our call for a government Inquiry was incorrect as it did not recognise the etiquette of devolution and in particular ignored the ongoing Penrose Inquiry in Scotland. After discussion with the firm, we changed this wording in two places to a version which satisfied them, but we left the phrase "a UK Government Inquiry" in one place as we judged it inappropriate in a policy document aimed at lay people to devote space to the minutia of political process regarding the devolved jurisdictions (as the firm had requested).

295. I stated in my reply to question 45 that the Policy was accepted by the vast majority of our members. Even assuming HS was representative of all Scottish members – which given the link to Scottish politics I am sure was not the case – this would have been 9% of our members disagreeing with one point. As we had considerable support and little material disagreement from our consultations, I feel justified in claiming that we achieved support of the vast majority of members.

296. Because the policy is important for understanding the full context of many of my answers in this statement, I include it here for ease of reference [**HSOC0029699** pages 2 to 4].

The Haemophilia Society Policy on Contaminated Blood

November 2012

Introduction

In the 1970s and 1980s, a large proportion of blood products supplied to patients by the NHS were contaminated with HIV or Hepatitis C viruses; at least 1,757[1] patients with Haemophilia have subsequently died from the effects of these viruses of the over 4,670 exposed to infection.

The risk of viral contamination, particularly from blood sourced in the USA, became known in the 1970s, although the existence of HIV and the lethality of Hepatitis C were not established until the 1980s. In response to the known risk, the Government in 1975 committed to the UK becoming self-sufficient in the main blood product used to treat Haemophilia (Factor VIII) 'within two to three years'. This promise was never kept. Heat treatment of blood products to destroy viruses finally became available in the early 1980s but was not fully implemented until 1986.

The NHS made no clear communication of the known risks to patients, and did not change practice to avoid use of blood products for patients who required treatment only infrequently and could have been adequately treated with safer alternatives.

Successive Governments have refused to hold a UK-wide Statutory Public Inquiry into these events. An Independent Inquiry under Lord Archer opened in 2007 and reported in 2009; this followed the procedures of a Statutory Public Inquiry but had

[1] The numbers of deaths and infected are the official numbers recorded at 2007 quoted in the Archer Inquiry Report. It is likely that there were additional deaths from infection which were not recorded as such.

no power to compel anyone to give evidence or to produce documents. Lord Archer made strong recommendations to Government, some but not all of which have been implemented. We recognise that there is an on-going Statutory Public Inquiry under Lord Penrose in Scotland.

Summary

This policy comprises three main requirements: an acknowledgement by the Prime Minister, a UK-Government Inquiry, and immediate interim steps to give equitable support to those affected.

This policy relates only to the Society's constituency of those with bleeding disorders. The Society recognises that people without bleeding disorders were also infected through whole blood transfusions, but it cannot express an opinion on the appropriate policy for this group.

The Society will review this policy after the Penrose Inquiry in Scotland reports in 2013.

Acknowledgement by the Prime Minister

The Society requires a public acknowledgement by the Government, given by the Prime Minister in a statement to Parliament, of the circumstances in the 1970s and 1980s which resulted in thousands of people being infected through contaminated blood. This should include recognition that mistakes were made by the Government of the time and by its Departments and Agencies, together with acceptance that this at the least creates the moral obligation on the Government to institute a payment and treatment regime for those affected which allows them to live in dignity and removes them from needing to rely on the benefits system or on a system of discretionary trusts. (They should of course still be able to access the benefits system if needed, as for the general population.)

Statutory Public Inquiry

The Society further requires a Statutory Public Inquiry into the circumstances which resulted in the contamination. The Inquiry terms of reference should include a focus on avoiding future medical disasters. Successive Governments have stated that they have learned and implemented all lessons from these events, but only a public review of the facts can prove this.

The Government must not, however, use the creation of such an Inquiry as an excuse for delaying rectification of current inadequate support for those affected, as outlined below.

Equitable support

Those infected often have conditions which prevent them working and which generate specialised medical needs. Both the infected and their families can have deep rooted psychological problems from the continued trauma of the experience; again this can require specialised treatment. Some partners have been infected through sexual transmission, and this has also led to some children being born with the infection, and these have the same needs as those infected directly. Where family members have acted as carers for decades with minimum support, this generates additional stresses and needs.

Given the immediate financial, medical, psychological, and counselling needs of many of those infected plus their dependants and survivors, the Society urgently requests that, pending any finding of fact and recommendations, Government implements an individual holistic needs-based and impact-based assessment for all those affected, with the goal of optimising clinical support, providing to the greatest extent possible for their emotional well being, and removing them from having to apply for further relief through the benefits system.

We believe that it is practical and affordable to run such a system for the few thousand cases which exist. If the Government queries the practicality of such individual assessment, we would suggest a trial to be run in a representative region of the country.

Pending the introduction of individual need-based and impact-based assessment the Society requires that the Government urgently rectifies gross inequities in the existing system, including:

- The process of applications by widows and dependants to the Skipton Fund, especially where medical records are missing. Where records are missing or inadequate, the "balance of probability" should be applied to make the assumption that an unexplained death of someone infected with Hepatitis C was caused by the virus's action on the liver and therefore qualifies for "Stage 2" payments.

- Medical evidence suggests that those individuals chronically infected with Hepatitis C, but with no visible damage to the liver, can still have chronic symptoms affecting their ability to earn a living and their need for support. The Skipton evaluation and payment regime should reflect this need.

- Recognition that those infected in general cannot get life assurance at any practical price and either (i) implement a Government underwriting scheme to provide affordable assurance or (ii) provide continued payments to the dependants after death of the infected person as a substitute for assurance. The scheme implemented should also resolve the issue of mortgages below.

- A similar problem exists, although to a lesser degree, for mortgages. Where those infected cannot get mortgages because the lender will not recognise the security of income and/or demands life assurance, the Government should provide confirmation of income and/or a scheme of assurance or the equivalent as above.

- Many carers of those infected have given up their own earning capacity over years or decades and are now themselves in serious financial difficulty. The Government should provide independent support to such carers on a similar basis to that on which it supports those infected.

- Dependants and widows of "first" families where an infected person has remarried are currently excluded from the payment scheme. Where appropriate they should be included.

- Psychological and long-term counselling support should be provided as needed for infected persons and their families. Given the sensitive circumstances for individuals needing such support, the channel of application should be designed to be sympathetic to their psychological needs and dignity.

- There are discrepancies between the payment regimes of the Caxton Foundation and the Macfarlane Trust; these should be levelled up so that the basis of payment is closely comparable.

- Those affected can spend excessive time accessing urgent medical care. The NHS should provide a 'Platinum Card' to those affected and provide

training to ambulance and Accident & Emergency staff to recognise the card and provide care accordingly.

(Q47) How was the decision made to include campaigning groups in the formation of this policy? How were the Manor House Group and Tainted Blood chosen to participate in the formation of this policy? Why were these two particular groups chosen? Were other groups consulted in the formation of or feedback on this document?

297. As explained in my reply to question 46 above, we consulted as widely as possible in order to maximise the legitimacy of the final Policy. This naturally included the campaign groups.

298. Manor House and Tainted Blood were the two most prominent campaign groups. We also contacted the Contaminated Blood Group. Separately we emailed everyone on the Society's "contaminated blood contact list" as well as requesting comments from our members through our website and social media. As noted previously we also consulted HS.

299. In the small world of people impacted by Contaminated Blood, it seems likely that this circulation would have been communicated at second hand to anyone not already on our list of contacts.

(Q48) What form was the practical commitment to the Manor House Group and Tainted Blood intended to take? Did this materialise in the way in which it was intended?

300. There was no "practical commitment". We met them to discuss the policy, they suggested changes to the policy, we agreed or disagreed (but tried hard to find common ground), made changes in response, and they accepted the final policy as allowing them to continue to work with the Society.

301. We did not ask them to endorse our policy and we did not ask them to change their policies. The exercise was to maximise the acceptability of the policy within the affected community (while meeting the Society Board's requirements) and to let us continue to work together with the campaign groups. In this the exercise was completely successful.

(Q49) Was the final version of the Contaminated Blood Policy sent to the Government? If so, how did they respond? Was any such response relied on? If so, how?

302. I am sure that it was sent to the Secretary of State for Health and potentially other ministers, but I have no personal recollection of this. It would have been sent by Chris James with my approval. I have no recollection of any reply.

(Q50) How was the document received by the haemophiliac community? How was the document received by other campaigning and haemophilia groups?

303. The only group which expressed a negative opinion was Contaminated Blood which felt that we had not adequately responded to their suggestions for changes in the policy. My memory is that this did not reduce cooperation with them afterwards.

304. There were only a few isolated comments from members, which was to be expected as the policy was established to draw a line in the sand, not as a document which was going to be actioned by the government any time soon.

305. The reaction of HS is described above.

306. To reiterate, establishing the policy was part of our strategy. Almost three decades of campaigning by politicians, campaign groups, and individuals, with the involvement of the Society had failed to achieve justice for those impacted by Contaminated Blood. We were not going to change that overnight, but we could do our best to be more effective going forwards.

(Q51) It was raised by the Tayside Group [HSOC0015214] and the West of Scotland Group of The Haemophilia Society Scotland [HSOC0015216] that the timing of the publication of the Contaminated Blood Policy "could have a detrimental impact on the…deliberations of Lord Penrose". Did you consider these beliefs to be accurate? Did you postpone the timing of the publication following these requests? Please detail your reasons. [You may wish to refer to *HSOC0015213* to assist you.] What was the effect of your decision?

307. I did not and I do not consider these beliefs to be reasonable or indeed well thought through. The deliberations of Lord Penrose were within the rigorous framework of a Scottish Public Inquiry and it seemed highly unlikely that they would have been impacted by a publication from the Society over 20 years after the events in question. (The Penrose Inquiry scrutinised events between 1974 and 1991.)

308. The conjunction of identical approaches from two groups after we had rejected HS's request to remove the demand for an Inquiry from the policy - and two months after we had originally requested comments - strongly suggested that these approaches were part of an orchestrated campaign rather than sudden spontaneous insights.

309. We did not delay publication.

310. As a general comment, some individuals held a belief that the Society had high visibility in government circles, whereas the truth was that the government and its agencies took almost no notice of us unless we could get independent political leverage – eg from Lord Morris and the Archer Report or from the later success of Alistair Burt with the APPG.

(Q52) How did campaigning efforts proceed after the publication of the Contaminated Blood Policy?

311. I have already answered detailed questions on our advocacy efforts above, particularly in sections 4.3 and 5.1, but also elsewhere.

312. I would note that in the end – due at least in some small part to the Society's support of the APPG and Alistair Burt - the government apologised and initiated this Infected Blood Inquiry and made at least some improvements in the support framework, although as these post-dated 2015 I am not aware how fully these improvements satisfy the issues which our policy identifies or how well they meet the needs of the infected and affected communities.

(Q53) Please provide detail on the Contaminated Blood Support Group. Who did it consist of? What was the purpose of the Group? What were the aims and objectives of the Group? How did it communicate with its intended audience and the haemophiliac community?

313. I have no recollection or record of this group.

314. Even if I did, I would never have known the detail asked for in the question.

5.3 CAMPAIGN FOR AN INDEPENDENT PUBLIC INQUIRY

(Q54) During your tenure, what role, if any, did the Haemophilia Society play in seeking an independent public inquiry? Please set out chronologically the Society's campaign and or involvement in the campaign for a public inquiry.

315. The focus of the Society's advocacy activity throughout my tenure up was on getting the government to improve the support given to those infected and affected by Contaminated Blood. I have detailed in my answers above various activities we engaged in in this, for example in section 5.1.

316. In late 2013 Alistair Burt MP obtained a commitment from the Prime Minister, David Cameron, that the government would revisit the subject of Contaminated Blood, both from the perspective of reviewing the support in place for those affected and from the perspective of reviewing the historical events. We were already in contact with Alistair Burt through his involvement with the APPG, and we supported him with detailed information on the history of Contaminated Blood and on the shortcomings of the systems of support. We did not press him on the issue of an Inquiry.

317. As per our Contaminated Blood Policy discussed in detail above and included in full under my answer to question 46, we said that there should be an Inquiry but that this was a lower priority than equitable support for those impacted. We followed this prioritisation in our advocacy, and although we included a demand for an Inquiry in our communications we made clear that that this should be after necessary improvements in support

318. The Prime Minister's commitment on Contaminated Blood in 2013 changed the overall picture, but we still prioritised reform of the support system over an Inquiry.

319. Thus, in my meeting with Earl Howe in November noted in my reply to question 31, I said:

> "The Prime Minister's commitment on investigation of "what happened" should be considered in the light of the Archer Inquiry and the Penrose Inquiry report due next March. If the government is willing to have an independent judge-led review taking these inquiries as a starting point, with a limited analysis of additional evidence, it may be possible to reach a report acceptable to all parties within a reasonable time and cost budget."

320. This reflects the fact that, while we wanted an Inquiry, we were concerned at the likely length of a full Inquiry (with the impact of that on the affected community) and of the potential for the Government to use waiting for an Inquiry to report as an excuse for not rectifying the support system immediately.

(Q55) What discussions were held with the Government with regard to an independent public inquiry? What, if any, reassurances were received from the Government? Did the Society's approach change in light of any such reassurances?

321. I wish that the Society had had the capacity to engage the Government in discussion. As should be clear from the answers above, we were lucky if we got a useful reply when we wrote to a government minister. Even where ministers made commitments to the Society – for example on implementing the recommendations of the Archer Report or on obtaining an investigation of mortality and morbidity in "Stage 1" Hepatitis for the Contaminated Blood haemophilia cohort - these were not always seen through.

322. With that preamble, the direct answers to the questions are:

323. No discussion were held.

324. No reassurances were received

325. The third part of the question is therefore not relevant.

(Q56) How prominent was the campaign for an independent public inquiry in the Haemophilia Society's campaigning efforts?

326. This duplicates question 54, which I have answered above.

(Q57) Please detail the disagreement between the UK Haemophilia Society and the Haemophilia Society Scotland over the campaign for a UK Government Inquiry which led to resignation of the Scottish Management Committee [STHB0000405]. Please detail the impact of this change on both organisations.

327. This question assumes that the disagreement over the wording of our Contaminated Blood policy was the driver for the resignation of the HSMC. In fact, correspondence at the time and later suggests that this was not the driver, but that it was a reflection of an antagonism to being a part of a UK-wide organisation and a convenient pretext for manufacturing a break. For example, an email to me dated 28 May 2015 from the Chair of HS evidences this (Exhibit WITN3092025).

328. Moreover, it can be seen from the detailed description below that the Society considered the various points raised by HS carefully and made several changes in

the draft Policy in recognition of these. A reasonable person might judge that this made the Policy compatible with HS's main underlying requirements.

329. The sequence of events regarding the inclusion of the demand for an Inquiry in the policy was as follows.

330. As described at some detail in my reply to question 46 above, the Society consulted widely over the first 8 months of 2012 when it established its policy on Contaminated Blood. This included a discussion with HS in, I think, June 2012.

331. In this discussion, HS claimed that its experience with the Penrose Inquiry gave it the unique insight into the effects of an Inquiry, from which they knew that a UK Inquiry would be bad for the Contaminated Blood community, and they asked for the demand for an Inquiry to be taken out of the policy.

332. In September, the board reviewed all comments received on the draft policy. By then HS had submitted a comment in writing to make the point that we should not include the demand for an Inquiry.

333. I would note that at that time we had appointed a member of the HSMC to be a Society trustee to try to ensure that there was good communication, and she was present and took a full part in the discussions at this board meeting. This included presenting the comment from HS.

334. The decision of the Board was to retain the demand for an Inquiry, which the trustees had included in each draft. From memory, the key reasons were:

(a) There was no request from outside Scotland to remove this. On the contrary, various individuals, both campaigners and people not involved in campaigning, explicitly supported the demand for an Inquiry, and it had been a central request in most campaigning over the years.

(b) Although the Society could not force the government to hold an Inquiry, if we did not demand it we would be giving the government the perfect excuse not to hold one.

335. The body of the minutes of the Board meeting (Exhibit WITN3092022) states:

"There was a lengthy debate on whether the Society should be calling for the Government to establish a Public Inquiry. It was agreed that it should."

336. A detailed appendix to the minutes reviewed each comment we had received on the policy, and explained the decision on each. On the HS comment the minute was:

337. "3. (From the Haemophilia Scotland Management Committee) Public Inquiry – Haemophilia Scotland does not support the call for a further public inquiry into the disaster, even if it were only to apply to England and Wales. The reasons are:-

- What is now needed for those affected is tangible action and better support financially and otherwise, not measures that would build in further delay to securing that. Having just in the previous paragraph called for an apology and such tangible support, government would instead have to 'await the findings of the Inquiry'.

- Such an Inquiry would take years to first secure, and then report. That delay means any answers would come too late for many of those affected who remain alive at present. It would also potentially allow Scottish Government to delay implementing any provisions following on from the Penrose Report. (See previous experience following the Lord Ross report and launch of Skipton).

- The Terms of Reference of any Inquiry are crucial. If they are too narrow questions remain unanswered and patient frustration is fuelled. If broad ToRs are set the Inquiry could last a very long time and even then frustrations are likely to be fuelled as the Inquiry Chair may interpret the ToRs and decide not to go into areas campaigners would prefer them to.

- Expectations could be raised by the Society such an Inquiry is likely, potentially fuelling further disappointment. There are no indications from either the Coalition or any of the major political parties that such an Inquiry is achievable.

- The Haemophilia Community needs to move on. Following the report of Penrose and any consequent action that would relate to a 'payment and treatment regime' called for at least North of the Border, the Society's strategy could focus upon extending any provisions across the rest of Britain and in particular initially Northern Ireland.

- The resourcing implications for the Society are huge if a meaningful Inquiry were to be achieved, resources which it is hard to see could be devoted without cutting back on other areas of the Society's work.

- While some of those affected by the disaster have emotional needs relating to such an Inquiry, others wish to move on and have done so and would prefer not to reopen the doubts, angst, frustration and bitterness of their plight.

Note: There was a great deal of debate on this issue but the call for a Statutory Public Inquiry remains in the Policy, reflecting a belief that those who wanted an Inquiry had a right to the Society's support. In response to the Scottish comments, we have added statements (i) that the Policy will be reviewed following report of the Penrose inquiry (ii) that the instigation of an Inquiry should not be used by Government as an excuse for delay in correcting inequities and (iii) the terms of reference of an Inquiry should include preventing future disasters"

338. As explained in my reply to question 46, subsequent to the September board we were approached by HS with an opinion from a respected Scottish firm of solicitors that the wording of our call for a government Inquiry was incorrect as it did not recognise the etiquette of devolution and in particular ignored the ongoing Penrose Inquiry in Scotland. After discussion with the firm, we changed this wording in two places to a version which satisfied them, but we left the phrase "a UK Government Inquiry" in one place as we judged it inappropriate in a policy document aimed at lay people to reference in detail the minutia of political process with the devolved jurisdictions (as the firm had requested).

339. In its resignation letter, the HSMC quoted our failure to follow this legal advice exactly as a contributory reason for their leaving. Chris James circulated the minutes and appendix of the September Board to the Trustees including me by email (Exhibit WITN3092023). He also circulated the draft policy as it was following the board meeting (Exhibit WITN3092024).

Consequences

340. The HSMC and HS as a part of the Society ceased to exist, and the individuals reconstituted themselves as a new Scottish charity, taking the name "Haemophilia Scotland" with our permission.

341. Following the departure of the HSMC, the Society continued to provide services to its members in Scotland, and these improved after 2012 along with general improvement in the Society's performance across the UK. However, we were weakened in our ability to engage with the Scottish government and NHS Scotland. We agreed to coordinate with the new HS in our contacts with these. In the Scottish political context there was sense in a Scottish organisation taking the lead in this, but because we were involved with rare diseases the overall effect was probably to create duplication of effort and greater costs. We also cooperated with the new HS in different activities, as we did with other organisations whose aims overlapped ours.

342. I cannot comment on the activities of the independent HS charity.

SECTION 6: INTERACTION WITH TRUSTS AND SCHEMES

(Q58) During your tenure, what was the Haemophilia Society's position, if any, with regards to the compensation structure for haemophiliacs who were infected with hepatitis and/or HIV as a result of contaminated blood products? If this changed over time, please detail when and why.

343. My replies above in Section 5.2 re our Contaminated Blood Policy and the Policy itself, and my answers to other questions, for example question 27 relating to Hepatitis C "stage 1", give a reasonable picture of our position on these matters.

344. I would note in passing that many people with haemophilia consider it insulting to call them "haemophiliacs" as if they were defined solely by their medical condition. I respectfully suggest that the Inquiry uses the term "people with haemophilia".

a. **Was the Society's position communicated to the Government? Was there a response and if so what was it?**

345. This duplicates question 55, which I have answered above.

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

346. This duplicates question 55 and other questions which I have answered above. In short, the Government made no assurances to the Society. (David Cameron's commitments in 2013 and 2015 were to the public at large.)

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

347. As answered in question 55, the government did not make statements and assurances.

d. **The Inquiry is aware that the Society was critical of the way in which the financial trusts and schemes were run, and were aware of the difficulties members experienced in securing assistance. Please explain how the Society presented the financial trusts and schemes to members of the Society, and how it communicated the process for applying for financial aid to its members. Did this change over time? If so, please detail how and when.**

348. I do not understand what the Inquiry means exactly by "Please explain how the Society presented the financial trusts and schemes to members of the Society". I explain here how the Society informed its members about the process for applying to the trusts during my tenure. I assume that at the time when each trust was originally set up, there was detailed communication from the Society to its members, but I have no direct knowledge of this.

349. The Society on its website and from time to time through HQ informed its members (and others) about the processes for applying to the trusts.

350. When members or others contacted the Society with difficulties in getting the trusts to respond, the staff tried to help. In some cases I got involved in writing to trusts on behalf of members.

e. **When you joined the Haemophilia Society, how many of members of the Board of Trustees or other committees in the Haemophilia Society were also involved in trust and schemes at board or committee level? If this changed during your tenure, please detail this.**

351. The society appointed 3 trustees to the Macfarlane Trust (which had been 4 prior to 2012), of whom one had to be a trustee of the Society. So one member of the Society Board would have been a Macfarlane Trustee. In 2015 the Chair of Macfarlane announced that henceforth the Society would not be asked to appoint trustees.

(Q59) Please detail your involvement with the trusts and schemes in your role at the Haemophilia Society.

352. Except for involvement in appointing some trustees to Macfarlane, I had no involvement with the trusts and schemes other than as external organisations with which we communicated or interacted from time to time. In particular, I was not involved with any of their internal decision making or processing activity.

6.1 CRITICISM FROM CLAIR WALTON

(Q60) Do you consider that the Haemophilia Society was independent from the Trusts and Schemes? If so, how did it maintain its independence? [*WITN1589001, paragraph*

353. Yes, I consider that the Society was independent from the Trusts and Schemes.

354. The board of the Society managed its affairs in accordance with charity law. There was full disclosure to the board of which trustees of the Society were trustees or beneficiaries of Macfarlane or another trust. (For simplicity I refer in the rest of this reply only to Macfarlane.)

355. There were undoubtedly conflicts of interest, particularly when the majority of the board was critical of the trusts (as was often the case when these matters were discussed). However, I cannot recall any case in which this led to a practical problem – the Society board would take soundings from all the trustees excluding the trustees who were also trustees of one of the trusts and would reach a conclusion.

356. Trustees of a charity have to act on behalf of the beneficiaries of the charity. Therefore anyone who was a trustee of the Society and of Macfarlane had to act for each board of trustees for the benefit of the beneficiaries of that charity. This meant that the Society could not instruct its trustees how to vote on the Macfarlane board.

357. The Society and Macfarlane each imposed a duty of confidentiality on its trustees. This meant that the Macfarlane trustees could not report back to the Society board. This also presumably created difficulties for these trustees, but it was necessary to maintain independence on both sides.

358. The benefit of the Society appointing a trustee to Macfarlane who was also a trustees of the Society was that Macfarlane got a capable trustee who was aware of current issues among the infected community – although they could not break confidence to discuss detail. We discussed this at the board more than once during my tenure and decided that despite the difficulties and our strong reservations

about Macfarlane it was better for the Macfarlane beneficiaries that we should supply trustees. (Of whom one was also a Society trustee.)

6.2 RELATIONSHIP WITH THE MACFARLANE TRUST

(Q61) Please detail your involvement with the Macfarlane Trust, and the relationship between the Haemophilia Society and the Macfarlane Trust.

359. As per various answers above, I (and the Society) had no role in the Macfarlane Trust, other than that the Society appointed trustees to Macfarlane. (This was 4 pre 2012 and then 3, and was ended unilaterally by Macfarlane in 2015.)

360. As per my reply to question 69, Roger Evans the Macfarlane Chair sat in on our interview of candidates for Macfarlane Trustee in September 2012. He did not have a vote in our decision on which candidate to accept. I coordinated with Roger directly in the run up to our interviewing of candidates for later vacancies, although I do not recall if he also sat in on these.

361. We interacted with Macfarlane as we did with other organisations such as the DoH and HS, through periodic written communication, telephone conversations, and meetings. Our CEO took the lead role, but I was involved in a small number of courtesy meetings with Roger Evans. (And a small number of phone calls with him, which I think were purely to synchronize these meetings.) From my general recollection – I cannot be precise - at most 2 of these meetings were just Roger and me, the others – probably 2 or 3 – included our CEO and Jan Barlow, the Macfarlane CEO. (This excludes the trustee interviews.)

362. I cannot recall the exact content of the meetings above. I (or our CEO) would have fed back the general unfavourable reports of Macfarlane that we received from our members. We would have asked for feedback on the situation within Macfarlane and on what they were hearing from the DoH. As these were informal meetings with the Chairs present, we would probably not have got down to specific cases or requests. I would have expressed the wish that Macfarlane could improve its processes, treat its beneficiaries in a way in which they felt that they were receiving respect, sought to be more transparent, and sought greater funding from the DoH – but these meetings were not the forum for demands or action plans.

363. If we wanted to make demands or go through detail and action plans, this happened in writing or in one-to-one business meetings between the CEOs.

364. I exchanged emails with Roger on various occasions, particularly after March 2015 when Roger refused to communicate with Liz Carroll. I shared these emails with Liz.

365. After the Macfarlane Trust initiated legal proceedings against the Society in February 2015, I immediately called Roger to try to resolve the situation promptly and sensibly, but he did not answer or return my calls.

366. Also as noted above, from time to time I wrote to Macfarlane or another trust on behalf of one of their beneficiaries.

367. Around the start of my tenure Chris James as a guest attended an open meeting for Macfarlane beneficiaries held by the Trust itself in connection, I think, with its getting feedback on its plans to distribute the reserves it had accumulated.

368. There were probably other occasions when our CEO and Jan and/or Roger were present at meetings held by the DoH or possibly the APPG.

(Q62) Please outline the role that the Haemophilia Society played in the operations of the Macfarlane Trust. To what extent, if any, did you or other members of the Haemophilia Society have an influence over the running, functions, processes, aims or objectives of the Macfarlane Trust?

369. The answer to question 61 covers most of this question.

370. The Society played no role in the operations of the Trust, except for appointing trustees.

371. Except for the obvious exception of the Macfarlane trustees whom we appointed (but did not instruct or receive information from), to my knowledge no member of the Society had "an influence over the running, functions, processes, aims or objectives of the Macfarlane Trust". It remains logically possible that some other Macfarlane trustee or staff member was a member of the Society, but I am unaware of any such case.

(Q63) Please confirm if you attended Macfarlane Trustees meetings and any other(s) you attended and, if so, please also confirm your role at those meetings. If you were a trustee, please explain how you came to be appointed and for what period you were in that role?

372. I did not attend any such meeting

373. I was not a trustee

(Q64) How often did the Haemophilia Society and the Macfarlane trust meet? Please detail how often the two organisations communicated.

374. My meetings are covered in my reply to question 61.

375. The Society CEO met the CEO and Chair of Macfarlane (Jan Barlow and her predecessor Martin Harvey, and Roger Evans) at irregular intervals. I would guess a couple of times a year face to face with the CEO – but I do not know exactly.

376. Our CEO would have met with the Macfarlane CEO infrequently for formal business meetings.

377. As noted in a previous answer, there may have been occasions when I or our CEO were present at meetings held by the DoH or APPG where The Macfarlane Chair or CEO was present.

378. Our CEO (and possibly other staff members) would have communicated with Macfarlane if there had been any relevant issues, including following up on behalf of individual Macfarlane beneficiaries. The CEO would have summarised to me any contact other than over administrative issues.

(Q65) Please detail the overlap between the Macfarlane Trust and the Haemophilia Society, including the overlap in personnel, roles and responsibilities. Do you consider that there was a sufficient level of separation between the Macfarlane Trust and the Haemophilia Society to ensure that each organisation adequately supported its recipients and members respectively?

379. Charity law requires trustees to act on behalf of the charity's beneficiaries, so that the Society had to act for the benefit of people with bleeding disorders and their families, rather than its members, although of course there was a large overlap.

380. There was no overlap of personnel, roles, and responsibilities, with the exception of one trustee as explained below as well as in various previous answers.

381. The Society appointed 4 trustees of Macfarlane, reduced to 3 at the start of 2012. One of these trustees had to be also a trustee of the Society. The DoH appointed 3 other trustees, and the remaining 3 were appointed by the Macfarlane board itself. I believe that this is a standard way of structuring the boards of such organisations in order to achieve a diversity of views, experience, and skills, and hence to create independence through a need to balance different opinions.

382. As per my reply to question 61, Roger sat in on our interview of candidates for Macfarlane Trustee in September 2012.

383. The trustee who served on both boards was constrained by confidentiality from passing on information, and in contributing to decisions on each board was required by law to consider interests of beneficiaries of that organisation only. This certainly would have created difficulties at times for the individual, but my observation over the 4 years was that it worked well in practice.

384. On the specific question asked above, I therefore consider that there was a sufficient level of separation.

385. However, on the basis of extensive evidence I saw over 4 years, I do not consider that the Macfarlane Trust adequately supported its "recipients".

(Q66) Please detail the appointment process for Macfarlane Trustees, and the composition of the board, including the numbers appointed by the Macfarlane Trust, the Haemophilia Society and the Government. Please also detail if this changed during your tenure, and if so, when and how.

386. As per my answers above, from the start of 2012 the Society appointed 3 trustees to Macfarlane, the DoH appointed 3, and the Macfarlane Board itself appointed the remaining 3. (Prior to this the Society appointed 4.)

387. In March 2015 Roger Evans, the Macfarlane Chair, wrote to me to say that henceforth Macfarlane would not ask the Society to appoint trustees. If this decision had been passed by the full Macfarlane Board I strongly believe that one or more of the Society-appointed trustees would have resigned. I therefore strongly suspect that the change was made outside the normal governance processes of Macfarlane, and that it was possibly not legally valid. We did not pursue this during my period of office. The Inquiry may wish to review the minutes of the relevant

board meetings of Macfarlane and check with the Society-appointed trustees to satisfy itself on this point.

388. When there was a vacancy for a Society-appointed trustee, we would advertise to our members (and I believe that Macfarlane would advertise to its beneficiaries) and our Nominations Committee would interview candidates and recommend to our board who should take the role, the board then making the appointment. Where the vacancy was for the trustee who was also a Society Trustee, I think that our board decided without the Nominations Committee.

389. As per my reply to question 61, Roger sat in on our interview of candidates for Macfarlane Trustee in September 2012. He may have made comments in our discussions of the candidates, but would not have voted on the outcome. Roger and I also exchanged emails where we agreed logistics for the interview process.

(Q67) Did the Macfarlane Trust reject any of the nominations for Trustee from the Haemophilia Society?

390. I am pretty sure this did not happen during my tenure.

(Q68) Please detail the relationship and the nature of the discussions that you had with Roger Evans, Jan Barlow and any other members of the Macfarlane Trust.

391. I cannot remember details of the discussions. As I have mentioned in previous replies, I had one or two introductory "social" meeting with Roger and two or three meetings with Jan, with Roger present at one or two of these. I do not think these meetings got down to great detail and I certainly do not recall major arguments, even though Roger and Jan knew that the Society was very critical of aspects of the trust. The real relationship with Macfarlane was held by our CEO. I saw my role as raising criticisms in general terms, while keeping a channel of communication open so that we could be direct in correspondence but perhaps work out a resolution to issues behind the scenes. I was clearly unsuccessful in achieving this.

392. I do not think I communicated with Jan outside these meetings.

393. I have found a few examples of written communications with Roger, in addition to practical emails about the appointment of trustees. Thus, in November 2013 after David Cameron met two of Alistair Burt's infected constituents, I wrote to Roger to inform him (Exhibit WITN3092026). This was ostensibly to keep him in the loop but (transparently) the actual intention was to make him consider that there would soon

be government pressure on Macfarlane to improve its behaviour. As another example, on 15 April 2014 Roger wrote a long email to me (Exhibit WITN3092027) detailing the funds Macfarlane would pay to beneficiaries in 2014/15. For some reason he asked us to forward this to Alistair Burt and the APPG Chairs – both of whom had publicly available email addresses - rather than sending it direct.

394. In March 2015 Roger wrote to me (**MACF0000059_011**) saying that (1) henceforth Macfarlane would not communicate with Liz Carroll but would address all communication to the Society to me and (2) Macfarlane would no longer ask the Society to appoint trustees. I replied after a cooling-off period to say that the Society had full confidence in Liz and that she would handle all communications with Macfarlane, and basically asking him to save me the trouble of passing on letters and emails by sending them direct. This was still not resolved when I left in November 2015.

395. **GRO-D** I maintained a professional, friendly demeanour.

(Q69) Please detail the level of Roger Evans' and any other members of the Macfarlane Trust's involvement with the Haemophilia Society and, if any, the overlap of responsibilities with the Macfarlane Trust. If you have already answered this question in other sections of your response, please identify the paragraph number(s)

396. During my time, as far as I remember, there was no involvement of Roger or other Macfarlane trustee with the Society, expect for (a) the Society-appointed Macfarlane trustee who also sat as a Trustee for the Society and (b) Roger's sitting in on our appointment of Macfarlane trustees as per my reply to question 61.

397. For the trustee who sat on both boards, there was a clear structure of separation of interests and communication by (a) confidentiality requirements imposed by each board (b) the legal duty of a trustee to act only in accordance with the aims of the charity. This is discussed above at some length in my answer to question 60.

398. As regards "overlap of responsibilities" between the Society and the Macfarlane Trust, I take this to mean areas where we shared responsibility for some outcome and/or collaborated in some way. There was no such area of shared responsibility.

399. Separately, Roger had been interim CEO of the Society sometime around 2008.

(Q70) Was there a difference in the level of communication between trustees who originated from the Haemophilia Society, or were still involved with the Haemophilia Society, and those who did not originate from the Society?

400. I do not understand this question.

401. If this relates to Macfarlane, once we appointed trustees to Macfarlane, confidentiality prevented us having any communication about their role there.

(Q71) Please explain in detail why it was considered that the Macfarlane Trust and the other support schemes was "not *fit for purpose*" in the letter to Ms Ellison on 10 February 2015 [HSOC0029441_*007*]? Why was a call made for them to be disbanded?

402. The wording of the question understates the clarity and force with which the Society stated its position in the letter referred to. I believe that it is best to answer the question by quoting from the letter itself:

> "We believe the current system of support provided by the five organisations (MFET„ The MacFarlane Trust, The Skipton Fund, Caxton Foundation and The Eileen Trust) funded by the Department of Health to support those affected by the contaminated blood tragedy is not fit for purpose. The Haemophilia Society believe they should be disbanded, and a new mechanism of support created, including a completely different team of people to administer future support.
>
> [...]
>
> As you know, the APPG report showed that overall levels of satisfaction were low with only 31% saying they were dealt with efficiently, 21% stating the support met their needs and 19% that support was given fairly.
>
> We have a great deal of contact with people affected by contaminated blood, and also occasionally meet with The Chief Executive and Chairs of The MacFarlane Trust and Caxton Foundation. The Haemophilia Society also nominate three Trustees to the Board of the McFarlane Trust. Although we do receive mixed views on the organisations, the overwhelming experience of those we speak to is dissatisfaction, distress or anger at the way beneficiaries of the organisations are treated.

Some of this is directed at the Department of Health in terms of the level of support provided, but much is focused on the lack of respect and understanding of the issues beneficiaries face by the staff of the these organisations, This was also reflected in the many personal stories relayed by MPs who spoke at the Back Bench Debate."

403. If the Inquiry would like more detail, then reading the summary or full version of the APPG report referred to in the letter to Ms Ellison (Exhibits WITN3092019 and WITN3092020) should suffice.

404. I would add to this

a) Our Contaminated Blood Policy (quoted in full in my answer to question 46 above) detailed some nine areas in which the overall support from the government did not recognise specific needs of the affected population or equitable treatment between different groups.

b) Beyond this, the government had ***never*** (to the best of my knowledge) carried out a needs assessment, so it had no way of knowing if its funding was adequate. Moreover, as the population of these affected aged, their needs changed and in general increased, and this had also never been analysed by the government.

c) The piecemeal structure of five trusts and schemes meant that there was inconsistency in treatment for different people, and also presumably added to the bureaucratic costs which diverted funds which could have gone to beneficiaries. (As did managing the trusts from expensive central London locations.)

d) By setting up trusts without direct oversight, the DoH failed to exercise its statutory duties (not to mention its moral responsibility).

e) Beneficiaries objected to receiving charitable support – and having to prove need at every stage and to compete for limited resources with other beneficiaries - rather than receiving support as a right, as would have been the case with other government benefit schemes.

(Q72) Please expand on the comment that there was "a *lack of respect and understanding of the issues beneficiaries face by the staff of these organisations*" [*HSOC0029441_007*]. Did the Haemophilia Society attempt to remedy this? If so, how?

405. The comment in the question "a lack of respect…" is borne out by the evidence in the APPG report referred to my reply to question 71 and appended as a document to that reply. In addition, it reflects the personal experiences of beneficiaries of "these organisations" over the years, as relayed to successive CEOs of the Society including Chris James and Liz Carroll, and as observed on occasion directly by myself. As examples of my direct observation, I note the correspondence with Claire Walton in question 60 and my reply to question 33 quoting the lady who had been told by a member of staff of Skipton that "she was lucky to be receiving funds from Skipton".

406. The Society (the CEO or sometimes myself) would write to the trusts on behalf of beneficiaries who approached us. In my conversations with the Macfarlane Chair and CEO and I raised the issue of respect and understanding in general terms, to explain why we were so critical, in the hope that they would take appropriate action. I believed that diplomacy was better than thumping the table – although in retrospect my approach was not successful either.

407. We advertised to our members through HQ and other channels that we wanted to hear of their experience with the trusts and that we would try to help as necessary.

408. We also attempted to remedy this through the statement of our Policy and through our advocacy, particularly through the APPG, which was one of the factors leading to the production of the APPG report quoted in the letter included in question 71 above.

(Q73) It is understood that you were present at a meeting on 4th February 2015 between Liz Carroll, Jan Barlow and Roger Evans [HSOC0029441_*003*]. Please set out in detail what took place at that meeting. Was a comment made that "the *Department of Health should wait before responding to Penrose so more people will have died and they will have less to pay out*"? If so, who made that comment? What was your reaction to the comment?

409. I strongly object to the wording of this question.

410. I will answer the question as if it reads: "Were you present…"… "if you were present, please set out in detail…"

411. For the avoidance of doubt I was not at the meeting in question.

412. Consequently I can give no direct confirmation of the comment.

413. The Society board minute for 4 February 2015 [**HSOC0029441_003**] states:

"Meeting with the MacFarlane Trust

LC met with Jan Barlow CEO and Roger Evans (Chair) of The MacFarlane Trust (MFT)."

414. The rest of the discussion minuted makes clear that only Liz was present for the Society. The minute quotes Liz as saying "Jan then expressed her opinion that the DH should wait for as long as possible before making any decision as more people will have died and there will be less people to pay and fight for payment."

415. My memory is that I and the trustees were disgusted that Jan should say such a thing, but not surprised, as she had a reputation among the beneficiaries as being callous and unthinking. (And as a board or individuals we had heard many examples reported.) We did not imagine for a moment that Jan was expressing a serious wish or recommendation or making an incantation – or that Liz believed her to be so doing; rather we thought that she was indulging in "humour" of exceedingly bad taste. Knowing Liz well, we trusted her fully and none of us questioned her account of Jan's statement. By February 2015, I personally had worked closely with Liz for over a year and had strong experience of her absolute integrity.

416. In an email with the trustees of the Society later that month (20 February 2015 Exhibit WITN3092028), I commented that the statement was "tasteless", a term also used by another trustee in a later email. This evidences my interpretation in the paragraph above.

(Q74) Please detail the discussions that led to the decision to the publication of the letter from Liz Carroll to Ms Ellison on 10 February 2015 [HSOC0029441_*007*]. Did you support the public release of the above mentioned letter?

417. The letter to Ms Ellison was part of the Society's advocacy and it – although obviously not its detailed content - had been planned as part of the APPG's production of its reports into the trusts. The publication of the letter on our website and social media was a part of this planned advocacy.

418. The letter was drafted by Liz after the board meeting on 4 February and was agreed with minor changes by the trustees by email. I agreed with the wording of this letter – there was an email in my name (Exhibit WITN3092029). Clearly, as Chair I had overall responsibility and should have realised that the remark she quoted Jan as

making could be potentially interpreted as libellous and that we could not prove it with two witnesses against one.

419. I supported the public release of the letter. There was an email debate amongst the trustees whether to include the offending sentence - precisely because it would offend our members - but the conclusion was that our members had a right to know what was said.

420. It is worthwhile pointing out that the Society was a tiny organisation with the equivalent of about 7 full-time employees. I was a volunteer as were the other trustees. We simply did not have the resources to submit every letter and publication to a lawyer.

(Q75) Roger Evans states in a letter sent to you on 17 March 2015 [*MACF0000059_011*] that the relationship between the Haemophilia Society and the Macfarlane Trust was "deeply *damaged*".

a. Do you agree with this assessment of the relationship at the time?

421. In retrospect, we clearly should not have included the offending statement in the letter to Jane Ellison, even though I believed it to be true – and still believe it to be true.

422. Conversely, Roger should have phoned me when he became aware of it in order to resolve the situation quickly with minimal costs and disruption. (And similarly he should have returned my subsequent phone calls.) GRO-D GRO-D

423. (It should be noted that although Macfarlane demanded that the Society paid its legal costs we successful refused, on the basis that it incurred these costs unreasonably.)

424. As a result of these actions, the relationship between the two organisations was damaged. However, in my opinion the damage was not irreparable, and could have been repaired GRO-D

b. Please detail what the state of relations between the two organisations was at that time and how it changed, if at all, for the remainder of your tenure?

425. Our relationship with Macfarlane Trust up to February 2015 was similar to our relationship with the DoH – we were privately and publically critical on various issues, but we met and corresponded with them civilly and cooperated usefully in particular areas such as appointing trustees.

426. For the remainder of my tenure, Roger Evans refused to have Liz Carroll communicate with him or any of his staff, and insisted on communicating with me. I politely suggested that this would not work to anyone's benefit, but we had not resolved this when I left.

427. Roger also wrote to me to say that Macfarlane would no longer ask the Society to appoint trustees. There was a vacancy as of the start of 2015, but we did not see this as an urgent issue since we hoped that the stimulus of the APPG report mentioned in my reply to question 71 (Exhibit WITN3092019 and WITN3092020) in the context of the Prime Minister's involvement would result in a rapid restructuring of the trusts.

c. **The letter also stated that "at *a board meeting on 6 March 2015, the board of MFT reviewed the way it intends to engage with the Haemophilia Society".* Please set out in detail the changes that occurred as a result of this review.**

428. See my answer to b. above.

429. However, note that I do not believe that a board meeting of Macfarlane could have stopped the appointment of trustees by the Society without at least one of our appointed Macfarlane trustees resigning. I also understand that the governance of the Macfarlane Trust at that time would have required it to get the Society's approval for any change to the Society's right to appoint trustees and I can confirm that we gave no such approval.

d. **What, if any, was the impact of these changes to:**

i. **The involvement of the Society in the Macfarlane Trust; and**

430. There was no involvement of the Society in the Macfarlane Trust other than appointing trustees. As above, after this incident Roger stated that Macfarlane would no longer ask the Society to appoint trustees. I do not know how stopping this played out after my departure in November 2015.

ii. The ability for individual beneficiaries to resolve issues with the Macfarlane Trust; and

431. I do not know the answer to this. We would have continued raising issues with the Trust at the request of our members. I have no knowledge of whether the Trust would have treated our intervention differently.

iii. The efficiency of the function and running of the Macfarlane Trust?

432. As I was not involved in the running of Macfarlane, this is a question I am unable to answer – I have no information on its efficiency either before or after.

(Q76) In [*MACF0000059_011*], on 17 March 2015 Roger Evans wrote to you informing you that the Haemophilia Society's right to appoint trustees to the Board of the Macfarlane Trust was removed in April 2012, and that the Board would not be inviting the Haemophilia Society to nominate a replacement appointment for one of their members. Please explain how the process of the removal of this right occurred. Was the Haemophilia Society notified at the time? Was a representative of the Society invited to discuss this matter?

433. To the best of my memory and knowledge, neither I nor the Society was notified in April 2012 or subsequently (until the letter referred to in this question) of any such change in the Society's right to appoint trustees, and the Society continued to appoint trustees up to end 2014 (and indeed was in discussion with Roger Evans about appointing a trustee to a vacancy in February 2015).

434. Similarly, I am confident that the Society was not invited to discuss this matter in April 2012.

435. If the Macfarlane Trust Deed was changed in 2012 as claimed in the letter, this would have required approval by the Macfarlane board. If this indeed happened, I am surprised that no Society-appointed Macfarlane Trustee chose to resign at the time. (Or, without breaking confidence since, a public document was involved, to have sent the revised Trust Deed to the Society.) Also, I believe that the governance of the Macfarlane Trust at that time would have required it to get the Society's approval for any change to the Society's right to appoint trustees, and I do not remember the Society giving any such formal approval.

436. I set out below an email from Roger to me in February 2013 (Exhibit WITN3092030) which shows that he considered that there was a fixed arrangement that the Society would continue to appoint trustees:

Meeting up

Roger Evans GRO-C **via btinternet.com**

Tue, 19 Feb 2013, 07:28

to bernardmanson, jan

Dear Bernard,
I have been meaning to follow up before now on our meeting on 7th Feb, but have been distracted by other things.

May I first say it was helpful getting together and exchanging views from our different perspectives.
[...]

Jan mentioned that Chris had said that in future the HS Board was looking for at least one of its MfT Trustee appointees to be a member of the HS Board. This has been the case for many years. It certainly was so when I was the HS interim CEO six years ago and has continued. We will, of course, be very happy for this to continue in the future

[...]

Best Wishes,

Roger

437. Similarly, Roger wrote to me on 12 January 2014 asking for "an update on progress with appointing a Trustee to the MfT Board, in succession to Kate Evans" and whether we were "at a stage when you require dates from me for the selection process." (Exhibit WITN3092031)

438. I would note that there was a perception amongst some of the Society-appointed Macfarlane trustees that Roger Evans was an over-dominant Chair, and unduly swayed some board decisions. I would suggest that his behaviour in February

2015 regarding the Jane Ellison letter - in going to lawyers to threaten the Society rather than phoning me first to try to resolve the matter peaceably - evidences such a tendency in his character.

(Q77) In your response to the above mentioned letter [MACF0000059_*051*], you state that you were unaware of the removal of the right. [MACF0000059_*092*] also shows that Liz Carroll was under the impression that the Haemophilia Society was still able to nominate at this time. What was your understanding of the basis under which the Macfarlane Trust came to remove the right of the Haemophilia Society to appoint trustees?

439. As per my answer to 76 above, I have no understanding of the alleged removal of this right.

(Q78) During your tenure, was this right restored? Was the Haemophilia Society invited to nominate a trustee to the Board of the Macfarlane Trust at any time after April 2012?

440. As per my answer to question 76 above, the Society appointed Macfarlane trustees in 2014 and was in discussion with Roger Evans in February 2015 about appointing a trustee.

(Q79) Did you encounter any other problems between the Haemophilia Society and the Macfarlane Trust during your tenure? If so, what were they and how were they resolved?

441. As regards "other problems", various of my answers above in this Section 6.2 and elsewhere show the issues we perceived in the activities of the Macfarlane Trust and of the steps we took to try to resolve these. If the Inquiry has further specific questions I can try to answer them.

6.3 GRANT APPLICATIONS

(Q80) Please provide details of your involvement in applications for financial assistance and support made by members of the Haemophilia Society to the Macfarlane Trust.

442. As per my answers above, if I were approached by a beneficiary of the Macfarlane Trust asking for help in an application, I would usually write a letter to the Trust (checking this with our CEO). I would generally copy these letters to the Society

CEO who would be involved in any follow up. The CEO would probably have been involved in many more cases, as they came to me very much by exception. Note that we did not check if the person involved was a member of the Society. I was generally not involved after my initial letter.

(Q81) What was the allocations policy in place at the Macfarlane Trust? Did the Haemophilia Society have a role in making grants to individuals and, if so, on what basis were the grants made by the Haemophilia Society during this time? Did this evolve over your time with the Haemophilia Society, if so, how did it do so?

443. I had no knowledge of the internal workings of the Macfarlane Trust, and I am surprised that the Inquiry is asking me about them. It should certainly have published its allocations policy, but to the best of my knowledge it did not.

444. The Society had a very small fund, the "Tanner Fund", which was made grants up to £200 to individuals who had hardship "on the recommendation of a medical practitioner or a social worker".

445. From memory, the application would come to the CEO and would be approved by one of our trustees, Kate Khair. I was never directly involved in these decisions as the sums were small and there was an issue of confidentiality. (Although I may have heard from Kate about particular cases.) I would have seen the total sums involved in the management accounts presented to each meeting of the Resources Committee and the Board. I was not involved in any change over my tenure.

446. The funds were from dedicated donations, initially from the Tanner family. From the Society annual reports, over the 5 years to March 2015 (Exhibits WITN3092002, WITN3092003, WITN3092004, WITN3092005, and WITN3092006) the Tanner Fund paid out an average of £1,487 per year, and it had a closing balance of £3,609.

(Q82) Did the Haemophilia Society have an input into whether particular procedures or items would be covered by funding from the Macfarlane Trust If so, how and when?

447. The Society had no such input during my tenure.

(Q83) What role did the Society play in making grants, or in making decisions about grants, on behalf of the Macfarlane Trust? To what extent, were you involved in these decisions? Was the Macfarlane Trust receptive to any such involvement?

448. The Society had no such role during my tenure.

449. As per various answers above, I (and the CEO) wrote on various occasions to Macfarlane regarding specific applications. I do not know how the Trust felt about these letters. My memory from conversations with the CEOs is that the Trust was generally not receptive to such intervention.

(Q84) Did you consider that the funding provided to the Macfarlane Trust by the Government was adequate? Please explain your answer.

450. No, I do not consider that the funding was adequate.

451. To the best of my knowledge, the government never carried out an analysis of needs of the infected and affected population, and therefore it is not possible to say what the total funding should have been. It also failed to adjust its estimation of need in line with changes as the population aged.

452. As highlighted in our Contaminated Blood Policy, there were whole classes of need which were ignored by the trust – for example that spouses had spent decades caring for beneficiaries and had not been able to work, thus losing any right to a pension.

453. The fact that the Trust implemented a highly bureaucratic process to analyse applications for funding and rejected many of these implies that the funding was inadequate even for the classes of need which the Trust was willing to consider.

(Q85) Did you, or any others within the Haemophilia Society or the Macfarlane Trust, raise any concerns or issues with the Department of Health about the funding, structure, organisation or running of the Macfarlane Trust, or about the involvement of the Department of Health, or about any other matter? If so please explain what concerns and issues were raised and what the response was received from the Department of Health.

454. As per various answers above, the government's commitment following the Archer Inquiry was to set up a structure whereby all stakeholders in the Contaminated Blood Community could meet with government (ie the Civil Service) to work through all issues, both medical and support. The vehicle established was the meeting of the Haemophilia Alliance with the DoH. However, the DoH refused to discuss issues other than medical, either through the Alliance or through other channels.

455. Although the Society raised concerns about the funding, structure, organisation and running of the Macfarlane Trust (and the other trusts and the overall system of support) with the DoH and various ministers, we received no response other than "this is not our responsibility" and we were unable to find a minister in the DoH or elsewhere who was willing to answer us.

456. We therefore worked with the APPG to progress this, culminating in the letter to Jane Ellison discussed in question 72.

(Q86) To what extent, in your experience, was the Macfarlane Trust independent from the Government/ the Department of Health? How much oversight or involvement did the Department of Health (or any other government department) have in relation to the activities and workings of the Macfarlane Trust?

457. I had no involvement in the running of Macfarlane and my experience of the Trust is therefore as an outsider.

458. In discussions with the Society, Roger Evans and Jan Barlow stated that the Macfarlane Trust was totally dependent on the DoH for its funding. However, I understand that their trust deed as charity enabled them to raise funds externally.

459. As reasonably well-informed conjecture, my belief is:

1) The Trust was in theory independent of the DoH – and as a charity had a duty to act only for the interests of its beneficiaries. However, as its grant was fixed annually it was in practice unwilling to do anything which would upset the DoH.

2) There was no direct involvement of the DoH in the Trust, except setting its budget and appointing some trustees. The Trust had effective operational independence, subject only to the constraint of funding. In particular, the DoH did not seem to oversee the Trust to ensure that it was fulfilling its responsibilities to beneficiaries. If so, this would seem a failure of the DoH to exercise its duty of care to the beneficiaries.

460. I believe that the Inquiry should review these points with the DoH directly.

6.4 RELATIONSHIP WITH OTHER TRUSTS AND SCHEMES

(Q87) Please detail the relationship between the Haemophilia Society and the remainder of the Alliance House Organisations ("AHOs"), namely:

a. The Caxton Foundation;

b. The Skipton Fund;

c. The Eileen Trust; and

d. The MFET.

461. As Chair, I was much less aware of the detail of our interactions with these organisations than with Macfarlane. This was partly because we appointed trustees only at Macfarlane, and I was directly involved in this. I believe that our CEOs would have had business relationships with the CEO of each of these organisations, as they did with the CEO of Macfarlane.

462. I remember that the Society had correspondence with these organisations as we did with Macfarlane, and I think that there may have been occasional CEO to CEO meetings or discussions. From time to time we would have beneficiaries of these organisations contacting us with problems in registering for or receiving grants, and we would follow up on their behalf. For example, with Skipton there were cases where medical records of someone deceased were lost, so that the family could not prove that Hepatitis was a causal factor in death, which they needed to do in order to receive a payment. There were similar complaints about the attitude of Caxton and Skipton staff as there were for Macfarlane.

463. I think that my memory here is of my general discussions with our CEOs or perhaps updates at the board - I do not recall any of this correspondence being escalated to me for direct involvement. However, it is possible that I was directly involved with a few cases as I was for Macfarlane.

464. Although I was aware of the details of these organisations' responsibilities when I was Chair, I can now only remember that Skipton was responsible for making non-discretionary payments to people diagnosed with Hepatitis C contracted through treatment by the NHS. I cannot remember any details of the other organisations.

465. As with Macfarlane, our major criticisms of these funds was their behaviour towards beneficiaries, the logic of the grants they gave, and the total funding available, as detailed in our Contaminated Blood Policy.

466. At one point we were approached to advertise for a trustee for the Caxton Fund, and I think we put an advert on our website and social media.

467. Regarding Skipton, a key issue we saw was the lack of an evidence base for the medical prognosis and the support needs for people with Hepatitis C who were in "Stage 1". They received very little support from the Skipton Fund, but the medical evidence suggested strongly that there was high mortality and morbidity in this cohort, and that they were often unable to work, creating support needs which were not being met.

(Q88) Please detail the opinion of the Haemophilia Society membership on the efficacy of the above mentioned AHOs. Did members consider the AHOs "*fit for purpose*"?

468. As a general comment, it is not possible to answer any question on the opinions of a large and diverse population without carrying out a dedicated polling exercise – which in this instance did not happen until we worked with the APPG on its questionnaire in 2014.

469. During my tenure there was a steady stream of complaints from beneficiaries (I do not know if these were all Society members) about specific actions or inactions of the various AHOs. The campaign groups also reported many similar incidents.

470. The opinion of the general membership was not relevant, as only a minority would have been beneficiaries of the AHOs.

471. It was not until the APPG report of January 2015 referenced in my answer to question 71 that we had a wide survey of beneficiaries of the AHOs. This decisively demonstrated that the widespread perception was that the AHOs were not fit for purpose.

(Q89) Did the Haemophilia Society have a similar level of involvement with the other four AHOs as it did with the Macfarlane Trust? Please detail any involvement or influence the Haemophilia Society had with each of these organisations, including whether previous or current members of the Haemophilia Society sat on the boards of these organisations.

472. This largely duplicates question 87 which I have answered above.

473. To summarise that answer, we had no involvement and little influence.

474. I do not know if any members of the Society were on the boards of these organisations. If they had beneficiaries on their boards, it is likely that some were Society members. We did not appoint trustees to any of these organisations.

(Q90) How often was the Haemophilia Society asked to get involved in applications made to the AHOs by individuals? If so:

475. I cannot remember enough detail to answer this. However, I saw these at least a few times a year, and there were certainly many more cases that I did not see as I did not normally get involved with operational activity.

a. Please provide details on which forms the involvement would take and what level of involvement the Society would have?

476. I cannot remember enough detail to answer this.

b. Were the AHOs receptive to any such involvement?

477. I doubt it, but I do not know as I was generally not involved subsequent to my initial correspondence on behalf of an individual. I would copy these to the Society CEO for his or her follow-up.

c. Did the likelihood of success or acceptance of the application increase? (See for example, [CAXT0000113_*009*]).

478. I do not know. However, I would comment that this email chain demonstrates the sort of attitude of the AHOs which was totally inappropriate. They seemed to me in this case to be more interested in bureaucratic procedures than in problem solving and basic humanity.

(Q91) Were the views expressed in [CAXT0000113_*009*] relayed to Jan Barlow and/or the Board of Trustees? What was the attitude or opinions of members of the AHOs if you, or another member of the Haemophilia Society, became involved with an application?

479. I note that Jan Barlow was copied into this email correspondence, so she would have had an opportunity to see it. Sadly, I do not know the impact where the Society became involved in an application.

(Q92) Please comment on any difficulties or shortcomings you encountered with the trusts and schemes during your time at the Haemophilia Society.

480. I have set out above the shortcomings the Society encountered with the trusts and schemes and I cannot add any further useful information.

481. However, I would point out that during the 4 years covered in this statement I was an unpaid Chair of an underfunded organisation struggling with the historic legacy of Contaminated Blood - alongside its core responsibilities as a patients' charity for a set of complex diseases. This historic legacy included causing a high proportion of our natural leadership and membership – adults with haemophilia and their immediate families –to be ill, busy as carers, or dead. This burdened us with extra responsibilities and costs and meant we had a smaller volunteer base and fundraising capacity.

482. The DoH expenditure on coffee and biscuits would have been greater than the total budget of the Society, and it should certainly have had the resources to manage its responsibilities in full. I suggest that the Inquiry investigates how during this period the DoH monitored the trusts and schemes which they established and funded, and whether they ensured that they were meeting the needs of beneficiaries whom their predecessors had contributed to infecting with lethal viruses.

(Q93) The Inquiry is aware that Jan Barlow was the Chief Executive of both the Macfarlane Trust and the Caxton Foundation. What are your views of one person being the Chief Executive of both organisations? Do you consider this overlap to have been detrimental to either one or both of the organisations? Was it beneficial to one or both of the organisations?

483. I had no direct knowledge of the detail, so I am answering this question from my business experience and my general observations of the trusts as recorded in my previous answers.

484. On a cost basis I would think that having a single CEO was the right structure.

485. There may potentially have been difficulties for other reasons, for example confidentiality.

486. This assumes that there was proper management and independent oversight from the DoH – the latter certainly did not exist.

487. GRO-D

488. I cannot say how this structure worked in practice or compare it with a hypothetical situation of two separate CEOs.

(Q94) Please comment on the efficacy of the Alliance House Organisations ("AHOs") you interacted with, and whether, in your view, they achieved their aims and purposes.

a. Were there difficulties or shortcomings in the way in which they operated or in their dealings with beneficiaries and applicants for assistance? If so, please describe them.

489. I have answered this in previous questions above, in particular in questions 87 and 88, and also in my response to b) below.

b. What, if anything, do you consider any of the AHOs, should have done differently?

490. They could have treated their beneficiaries with respect. They could have had periodic independent surveys of the attitudes and needs of their beneficiaries and acted on these. They could have published their criteria for giving grants. They could have created work patterns that were more responsive to applications and less bureaucratic. They could have simplified forms and been less intrusive in means testing. They could have recognised emergencies and had an escalation process to achieve immediate decisions. They could have challenged the DoH to carry out an analysis of needs so that they could better meet the needs of their beneficiaries. They could have published their trust deeds on their websites so that beneficiaries and others could better understand how they operated. They could have created and published a guaranteed response time and an independent appeal process also with a guaranteed response time. They could have published statistics of grants applied for and accepted/rejected along with key performance indicators such as the number of applications taking longer than N days to decide. They could have had a documented complaints procedure and published statistics of complaints.

491. Doubtless I could think of more if I had all the records of complaints from beneficiaries in front of me or if I had direct access at the time to the workings of the AHOs.

492. In the case of Macfarlane, it should in addition not have wasted funds on legal fees in February 2015 when the problem with the Society publishing a particular statement could have been solved by Roger Evans lifting the phone to me. (Or indeed returning my subsequent calls.) In my opinion his expenditure on these fees without first trying to resolve the issue directly with the Society was outside his legal powers as a trustee (ultra vires). In my role as a trustee of a charity I would have considered that spending £7,000 on legal fees without making some effort to resolve the situation without payment was against my legal duties. Where the issue was to protect someone's reputation rather than directly for the aims of the charity I would have been doubly reluctant. The money spent on these fees was effectively deducted from funds payable to Macfarlane beneficiaries.

493. The Inquiry may wish to investigate this.

SECTION 7: FINANCIAL ACTIVITIES

7.1 FUNDRAISING ACTIVITIES

(Q95) How, if at all, did the Haemophilia Society's fundraising activities develop over your tenure?

494. When I arrived the Society's previous dedicated fundraiser had left leaving a vacancy (although we had begun the process of recruitment), and the CEO raised funds from pharmaceutical companies as part of his role. In 2012 we recruited a staff member to combine fundraising and communication with members; this gave us a stronger base for community fundraising in subsequent years and in particular gave us a solid series of fundraising events which continued through my tenure and beyond.

495. In the summer of 2014 we recruited a dedicated fundraiser who further professionalised all areas of fundraising.

496. In 2013 we initiated a review of fundraising and discovered that we did not have the evidence base showing the impact of our activities that grant-making foundations would generally require. We put effort into this area, and by the autumn we had

done research and assembled an appropriate evidence base. This was an important part of our fundraising effort going forward.

(Q96) What proportion of the budget of the Haemophilia Society was raised through fundraising during your tenure?

497. Looking at the annual reports for 2011 to 2015 (Exhibits WITN3092002, WITN3092003, WITN3092004, WITN3092005, and WITN3092006), across the whole period, excluding government grants, legacies, and investment income, we raised 73% of expenditure from fundraising.

498. Including all these income items, we raised 111% of expenditure from income – ie our total income over the period exceeded expenditure by 11%. However, our planning was built on the prudent assumption that we could not rely on future income other than core fundraising, and in particular, as per a statement in each annual report, we could not rely on future legacies.

(Q97) Were Society members aware of where the money they raised or donated was being spent?

499. We published this in the Annual Report and Accounts (Exhibits WITN3092002, WITN3092003, WITN3092004, WITN3092005, WITN3092006, and WITN3092007), and we published information about various projects and publications in HQ (Exhibits WITN3092008, WITN3092009, WITN30920010, WITN30920011, and WITN30920012), our website, and social media. In addition, our Treasurer gave a financial report at the AGM and answered any questions. However, as would be the case in most membership organisations, I doubt if many members were aware of the detail unless they had a special interest.

500. I certainly never had a direct request from a member for financial information.

7.2 RELATIONSHIP WITH PHARMACEUTICAL COMPANIES

(Q98) 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.

501. From the annual report of the Society (Exhibits WITN3092002, WITN3092003, WITN3092004, WITN3092005, WITN3092006, and WITN3092007), the amounts raised from corporates (I assume almost all from pharmaceutical companies in the area of drugs for bleeding disorders – probably but not necessarily product) were for the years ending each March:

£	Corporate	% total	Total income
2011	183,874	28%	646,207
2012	114,882	17%	689,314
2013	174,179	20%	874,983
2014	66,559	8%	786,113
2015	205,077	31%	668,777
2016	317,684	49%	645,339

502. These corporate donations would have had to be compliant with the Society's "Commercial Funding Guidelines" which defined our policy for accepting donations from pharmaceutical companies and others. Unfortunately, despite repeated requests over the past three months I have been unable to obtain a copy of this document from the period of my tenure.

503. From memory of how the trustees and CEOs operated and of discussions about conflicts of interest, rather than direct memory of these Guidelines, I believe that the key provisions included:

- that there was no linkage between donations and any form of access to our members, other than our advertising the activity, project, or publication as being funded by the donor
- that donor companies had no editorial control over publications

- That no conflict of interest for a trustee or staff member arose from any aspect of the donation.

504. We would have publicly thanked the donor companies at the activity or in the publication which they had funded, and we would separately have thanked donors in HQ and in our Annual Report.

505. Donations would also have been be compliant with regulations for pharmaceutical companies, which became more restrictive over the years. Although I am not aware of details, these regulations strictly limited (or prevented) the companies promoting drugs or devices to patients.

506. Broadly, all funds from these companies were tied to specific projects; they did not give money for the Society's general needs. They funded staff costs only for their direct involvement in projects funded.

507. Many of the Society's information booklets would have been funded from such donations as would some events. However, I cannot remember any details of these or of other projects.

(Q99) 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.

508. At the start of my tenure, the CEO Chris James was the society's point of contact for pharmaceutical companies as regards our seeking funding. From memory, Rachel Youngman and then Liz Carroll took this on personally when they each became CEO, but when we recruited a dedicated fundraising officer in 2014 Liz handed this responsibility to him.

509. I do not know how or when these relationships were originally formed, but I think that Chris was in contact with pretty much every major pharmaceutical company from before my tenure. (It would have been easy to identify companies active in relevant products.)

510. I do not have details of who in each company were the points of contact, but typically this would be relatively stable with a department responsible for the company's budget for funding charities etc.

511. The method of communication would have been email, telephone, and meetings, and occasionally posted letters or documents – I do not know how else to answer this question.

512. I was not personally involved with any meeting or communication with these companies on funding. I would have bumped into company representatives at a few events, such as the WFH Congresses; to the best of my memory I never had more than a casual conversation in these instances.

(Q100) Was the Haemophilia Society allowed to determine where the funds from the pharmaceutical companies were directed, or was the money given for a specific purpose? 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?

513. To the best of my recollection, all money was given for specific purposes – eg a project or an information booklet.

514. Pharmaceutical. Companies – like other large organisations – would want to look good in order to make themselves more attractive to their direct customers or end customers. Donating to a patients' charity such as the Society to support projects or information booklets which supported people with bleeding disorders was a natural way to do this.

515. There was perhaps an expectation that the Society would be better disposed towards the company because of a donation, but since they knew that all their competitors were donating to the Society, and to similar organisations in other countries, I feel it unlikely that any company expected to get a particular advantage out of donating. However, if one company had not donated this would have been visible and might have created a bad impression. (The same would apply to the impact on patients or others who were the beneficiaries of the projects or booklets.).

516. By maintaining a relationship with our CEO, the companies doubtless got some general market intelligence, for example with some feedback on pronouncements by the DoH for example. This would not have involved any confidential information.

517. To the best of my knowledge, there was no explicit agreement by the Society to give anything in return for these donations except to associate the company's name with the relevant project so that our members knew who had provided the funding.

518. It should be noted that the companies had an interest in the Society's role in giving information to patients. For example, clinical trials were an important area for the Society, as there could be no progress in treatment without these. We were keen that companies would develop new therapies, which would require patients being willing to participate in trials. However, trials generally came with risks to the participants. (Some would just involve more tests without new drugs, but for patients with bleeding disorders even tests could have material risks). We had to be careful to stress both the benefit to the bleeding disorder community of these trials and the need for a potential participant to understand fully the risks involved. We periodically communicated with our members on clinical trials.

519. Thus in HQ of Summer 2013 [**HSOC0023056**] there was an article which began:

> "Without clinical trials new and improved treatments cannot be developed. Before a new product or a different approach can be introduced studies are carried out to find out if it is helpful or harmful. We, therefore, urge members to consider participating in clinical trials. However, any new treatment will involve risks for those who take part which need to be properly understood."

520. The article went on to explain the different phases of trials and to stress the importance of participants understanding and consenting to the risks.

521. Although these articles were not written with any involvement of pharmaceutical companies, they could have seen the Society as an important channel for educating patients on the benefits and risks of such trials.

522. Current prominence of "anti vax" propaganda shows the importance of having an objective source for information in these areas, which – rereading the 2013 article in 2021 - I believe the Society was.

(Q101) 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?

523. I am unaware of any such differences - which does not mean that they did not exist.

524. The companies would have had their own priorities, and they would have had differences on how they made their decisions on donations. Thus their budgets for donations might be larger or small or dedicated to the UK or shared with Northern Europe – and so on.

(Q102) A number of the Haemophilia Society Haemophilia Quarterly issues ("HQ") ended with thanking a range of pharmaceutical companies for their "*valuable support*" including Baxter Bioscience, Bayer, CSL, Behring, Grifols, Novo Nordisk, and Pfizer Pharmaceuticals [e.g. *HSOC0023056, page 40*]. Was that record a requirement of their funding? What was agreed in this regard? If so, how was this agreed?

525. My understanding is that we had no contractual agreement to thank donors, but that as a matter of courtesy – and to help maintain the relationship for the future – we would thank them in every appropriate publication and on the website. (Which I think is common practice for charities – and it also gives the charity credibility if it shows its links to major companies.)

526. The names above are given in alphabetical order, which I think shows that this was a courtesy rather a contractual arrangement (in which case you would have expected the biggest donation to be thanked first).

527. I also recall no check that we had thanked companies according to contractual arrangements, from which I deduce that there was no such arrangement.

528. This should have been covered in our "Commercial Funding Guidelines". As I explained in my answer to question 98 above, I have not been able to obtain a copy of this document to support this statement.

(Q103) Did the Haemophilia Society publish or disseminate any articles or publications in exchange for or with the expectation of receiving financial contributions, or any other benefit, by pharmaceutical companies? If so, please provide details of the nature of these articles or publications.

529. In my tenure, no.

(Q104) Did the Haemophilia Society refrain from publishing or disseminating any articles or publications in exchange for 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.

530. No such request came to me or the board, and I am unaware of any such request being made, accepted, or acted on.

531. During my tenure, the subject of potential conflict of interest involved in funding of a patients' charity by pharmaceutical companies was discussed at various times at Resources Committee, at the Board, and between me and the three CEOs.

532. The outcome was that we felt that we were successful managing conflicts of interest, but that as a strategic direction we wanted to build other sources of income to reduce our reliance on pharmaceutical companies. As per the figures shown in my answer to question 98, we did not really succeed in reducing this reliance during my tenure, but we did build other sources of income to put us in a better position for the future.

SECTION 8: VARIANT CREUTZFELDT-JAKOB DISEASE

(Q105) Please detail the relationship between the TSE Risk Assessment Sub-Group and the Haemophilia Society. [You may wish to refer to *HSOC0023058* to assist you.]

533. The TSE Risk Assessment Sub-Group was a government body and to my recollection we had no direct representation or relationship. As per the article cited, the Society wrote to the Sub-Group to challenge it on being willing even to consider non-consensual monitoring. (This would have been in the context of our awareness of non-consensual monitoring for HIV among people with haemophilia receiving blood product in the 1980s.)

(Q106) How much communication did the Haemophilia Society have with the TSE Risk Assessment Sub-Group. What were the Haemophilia Society's particular concerns or issues that were relayed to the TSE Risk Assessment Sub-Group? What was the TSE Risk Assessment Sub-Group's response to that communication from the Haemophilia Society?

534. I do not have any knowledge of the response to the letter from the Society or of any further contact with this Sub-Group. The Society did a lot of important activity monitoring offshoots of the DoH and the NHS, and would have had many communications such as the one described in the article. However, most of this activity was precautionary and involved only staff members checking on potential

issues, and in the end did not raise material issues needing to be escalated to the Chair or the Board.

(Q107) In relation to vCJD, the Society raised the idea of pre and post-test counselling [*HSOC0023058, page 29*]. Was this idea presented to any member or representative of the Government? If so, what was the response?

535. The article implies that this idea was in the communication to the sub-group, which would mean that it was presented to "representatives of the Government". However, I have no further knowledge of what happened in this case.

536. I believe that medical ethics now would require such counselling; I do not know what the situation was in 2012.

(Q108) Please describe any and all efforts made by the Haemophilia Society to campaign or advocate for issues associated with vCJD and particularly consent.

537. I remember that we raised various issues about vCJD with the DoH through the HA meetings. These included concern that people who had received blood product and been put on a register for vCJD were given notice that they were removed from the register without a clear reason being given. We took a highly precautionary view of the risks of vCJD and raised points about the safety of blood and blood products. (Many of these concerns were relayed to us by members.)

538. The Society saw itself as having a responsibility in this area, given the suffering of the haemophilia community from Contaminated Blood, which involved the government not taking available precautions against known risks of infections in the blood supply.

539. Apart from communicating to the APPG our concerns about the risks of vCJD and the need for more research, I do not think that we did other advocacy in this area.

(Q109) Did the Haemophilia Society engage in any campaigning efforts regarding vCJD testing or other issues experienced by members in relation to vCJD?

540. See my answer to question 108

8.1 RECOMBINANT

(Q110) Please detail what the position of the Haemophilia Society was on recombinant products during your tenure?

541. We stated that these should be available to everyone who needed them in the necessary quantities and that this should continue beyond the reorganisation of the English NHS as an Agency in 2012.

542. There was no clinical issue, as this was the accepted position among clinicians. However, there seemed to be a real issue about funding of product and of the possibility of commissioners identifying rationing of product as a cost-saving measure.

(Q111) Did the Haemophilia Society engage in any campaigning efforts to try to obtain widespread treatment with recombinant products?

543. I do not know what time period this refers to.

544. During my tenure, almost all people with haemophilia in the UK were treated with recombinant product which was not blood based. I believe that there may have been exceptions for particular patients for clinical reasons. I also recall that there were some very rare bleeding disorder conditions which were treated with blood based products.

545. Certainly the Society was in favour of recombinant product for all as this was the clinical advice as the best and safest treatment, but I do not recall there being a need for any campaigning for this in the UK as it was standard medical practice.

546. As per my answer to question 110, in 2012 we were concerned that commissioners or trusts might not fund product in full, and we raised issues around this with the DoH through the HA meetings.

547. In the event, I do not think any such reduction in supply materialised.

(Q112) Did the Society make any Government representatives aware of the Society's position? If so, what was their response? Did the Society rely on any such response? If so, how?

548. This question makes no sense as it does not state which position it refers to. If it refers to question 111, I have already answered there.

SECTION 9: OTHER ISSUES

(Q113) 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?

549. As the Inquiry and its Terms of Reference were set up after 2015, the Society had no responsibility or capability during my tenure to identify which documents were "relevant to the Terms of Reference of the Infected Blood Inquiry".

550. As with any organisation, there was a great amount of paper documentation created and this would have been archived for a few years and then destroyed on a rotating basis. (Subject to legal requirements such as keeping financial records for six years.)

551. The Society also had an archive of historic material dating back to its foundation in the 1950s. When we moved offices, there was a tidy up of the paper records but I remember discussions with Liz Carroll in which she said they were taking special care to ensure that the historic archive was transferred intact to the new premises.

552. During my tenure, there was (with the exception described in the next paragraph) no purposeful destruction of current records of the Society – say going back over the last six or seven years. By that time, most of the Society's records would have been electronic. Unfortunately, as I discovered when I tried to source documents from the Society to compile this statement, there was an inadvertent destruction of electronic records for 2012 and 2013 at some time after 2015. I understand that this was due to errors by the Society's IT service company, rather than by the intent of the Society.

553. I also discovered that the Society had a policy at least up to 2015 (which I was not aware of at the time) that when a staff member or trustee left, their email account was closed without records being kept. Undoubtedly, this would have destroyed information which would have subsequently have been useful to the Inquiry. I regret that this policy was in force, since for internal management purposes we should have kept emails from departed staff/trustees for as long as they were relevant, just as for continuing staff/trustees.

554. Related to this question, I respond here to the request for a written statement under Rule 9 of the Inquiry Rules dated 19 November 2020 that I provide the Inquiry with details of any documents that I hold that might be relevant to the Inquiry's Terms of Reference.

555. I can confirm that I hold a considerable number of emails on my personal account from the time when I was Chair of the Haemophilia Society, that is from November 2011 to November 2015. A limited number of these might be relevant to the Inquiry.

556. In my role as Chair I had an email address at the Society, which I used for official correspondence and for some other purposes. Alongside this, I usually used my personal email address for correspondence with staff and trustees of the Society, and I therefore have a large number of emails covering the generally insignificant points which arise in the day-to-day affairs of any organisation. However, these emails also include distribution to me of official papers of the Society, such as board papers and minutes. There is also some of my correspondence with people external to the Society, such as the Chair of the Macfarlane Trust.

557. The emails which I received in my role as Chair are filed in one personal directory, and therefore they are relatively easy to search if you know what you are looking for. In particular, it is generally straightforward to search for an attachment or an email from or to a particular person. However, as there are over 8,000 of these emails it is not practical to read through them to do a general search.

558. The emails which I sent as Chair are mixed in with my personal emails, and it is much harder to search for an individual email amongst these. I am not able to quantify the number of these sent emails. I also have some Word or PDF versions of documents which I was involved in drafting or which I downloaded as being important at the time. There are about 400 of these, but most of them are drafts or duplicates of official papers such as board minutes which should be available in final form from the emails. As the documents reflect a somewhat random subset of all of the documents I was involved in over four years as Chair of the Society, relatively few are directly concerned with matters of direct relevance to the Inquiry.

(Q114) 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.

559. I wish to explain two other matters under the headings "Other matters A" and "Other matters B" below.

560. Other matters A

I wish to draw to the Inquiry's attention to the fact that the evidence quoted in the Penrose Report shows clearly that government inaction directly caused some 500

or 700 deaths from AIDS, despite the government being aware at the time of the consequences of its inaction as evidenced by its own statements and commitments. The evidence also shows that an unquantified number of additional lives would have been saved had the government implement public health measures known at the time. I give the analysis below.

561. This is relevant to various of the Inquiry's Terms of Reference (ToR), but in particular to:

ToR 2. To ascertain, as far as practicable, the likely numbers of people who have been infected (directly or indirectly) in consequence of:

a. the use of infected blood; and

b. the use of infected blood products.

562. It is also relevant to various items on the List of Issues (LoI), for example:

LoI 49. What decisions and actions were taken, and what policies were formulated, by the blood services (whether alone or in conjunction with the Government/other NHS bodies/UKHCDO/pharmaceutical companies/others), which caused or contributed to:

a. the use of infected blood;

b. the use of infected blood products;

to treat people in the United Kingdom (or in any of the constituent parts of the United Kingdom).

Analysis

563. The Society's response to the Penrose Report (Exhibit WITN3092032) included an analysis of the comparative prevalence of HIV in people with haemophilia who received USA product and UK product. The analysis was based on detailed evidence in the Report, and concluded that the government's failure to implement its 1974 commitment to make the UK independent of foreign blood products "with a few years" resulted directly in some 500-700 excess deaths from AIDS.

564. In addition, the evidence in the Report shows that had the government implemented known public health measures in a timely manner, it would have saved the lives of

some people who died from Hepatitis C, and potentially some additional people who died from AIDS. However, the evidence does not allow quantification of the numbers involved.

565. We communicated this analysis to government in 2015, but received no response. I feel it is important that the Inquiry is aware of this analysis and has it reviewed by competent virologists or other relevant experts so as to see if the conclusions are justified.

566. **Assuming that the experts agree the conclusions, this should form part of the Report of this Inquiry since it establishes that the government's actions and inactions directly caused hundreds of deaths through Contaminated Blood.**

567. I copy below the relevant extract from the Society's Response to Penrose in May 2015. For ease of reading, footnotes in the original are embedded in the text in the appropriate place.

Only an earlier intervention by public health authorities could have created a situation in which the haemophilia physicians had the knowledge and the opportunity to prescribe consistently less risky blood products produced from UK voluntary donors. As discussed below, it may now be impossible to determine how much less risky such products would have been in preventing HCV infection and deaths, but they would have been substantially less risky in the period 1979 to 1984 as regards HIV infection, and on simple analysis explained below would have saved the lives of over half of the 900 people with haemophilia in the UK who have died from AIDS.

As evidenced by the Report, from the early 1970s the UK Government did recognise the greater risk of infection in commercially-sourced foreign blood products. In 1974 Dr David Owen, Secretary of State for Health, promised in the House of Commons to make the UK self-sufficient in blood products for Factor VIII within 3 years. The Inquiry evidence shows that had this been done, it would have directly prevented the infection with HIV of hundreds of those people with haemophilia who died from AIDS. The policy was never implemented. The chain of logic here is as follows:

1. By 1974 the Government recognised the greater infection risks of using foreign blood products (mostly made from commercially-sourced blood) to treat haemophilia, and accordingly committed to make the UK self-

sufficient in blood products for Factor VIII by the end of 1977.
[Footnote: Factor VIII is used to treat haemophilia A, which is to say about 80% of people with haemophilia. It is not clear from the Inquiry evidence how close the UK was to being self-sufficient in Factor IX used to treat haemophilia B, but according to the evidence the number of deaths by AIDS among people with haemophilia B was much lower than its 20% share of patients would have predicted.]

2. The risks were the known incidence of "post-transfusion hepatitis" and the known public health risk of future infective agents spreading through the blood supply.
[Footnote: Mortality from this hepatitis was greatly underestimated in the 1970s. The case made here is that the known risk of future infections should have been enough to drive public health measures to minimise exposure.]

3. The Government did not fulfil this commitment, and the Health Service continued to use massive quantities of imported product.

4. From 1979 UK haemophilia patients began to be infected with HIV/AIDS from blood product.

5. From studies done in 1984 and 1986, people treated with foreign blood product were from 4.5 to 6 times more likely to be infected with HIV/AIDS than those treated only with UK blood product.

6. Some 900 UK haemophilia patients have died from AIDS. A proper statistical analysis would be needed to estimate the deaths expected had all treatment been with UK products, but given the ratios above a range of about 200 to 400 seems reasonable.

7. The Government failure to deliver its own commitment thus caused the death of about 500 to 700 haemophilia patients through AIDS.

The situation with Hepatitis C infection is more complex, and it does not seem possible to estimate from the evidence in the Report the reduced mortality from Hepatitis C which would have occurred had the Government implemented its commitment on self-sufficiency. In this context it should be noted that although the Report gives evidence that UK concentrate had a high probability of being infected with HCV, it also raises the possibilities that:

- the size of the inoculum (the amount of virus with which the patient is initially infected) would have been lower in UK product
- the number of different genotypes of HCV would have been lower in the UK product
- UK patients may have been more likely to carry antibodies to common UK genotypes of HCV
- patients infected with fewer genotypes of HCV may have had a better prognosis
- patients infected with fewer genotypes of HCV may have responded better to treatments when they became available.

The Report evidence makes clear that there are no exact figures for the prevalence of HCV infection in the UK population in the 1970s and 1980s, although it appears that the trend was upwards year by year.

Further improvements in mortality and morbidity could have been achieved had the Government and its health agencies more promptly and more consistently implemented public health measures identified at the time. These included measures on the blood supply such as stopping donation from prisoners and screening high-risk blood donors, and measures on treating haemophilia patients, such as ensuring patients needing relatively little treatment received the lowest risk blood products, or, where possible from a clinical perspective, less effective but still adequate non-blood products.

It should be noted that whole blood or blood component transfusions were generally sourced from a single donor, and so, had high-risk donors been excluded earlier, materially fewer non-haemophilia patients would have contracted HCV from this source. Even with the lack of exact evidence on the historic prevalence of HCV, it should be possible to model within a reasonable range the lives which would have been saved by this simple public health intervention.

568. The rest of this section quotes verbatim from the Penrose Report to evidence the case made above. The Report paragraphs are in italics to further distinguish them from the Society's comments. Again, for ease of reading, a footnote in the original Report is embedded in the text in the appropriate place.

"1. By 1974 the Government recognised the infection risks of using foreign blood products to treat haemophilia and accordingly committed to make the UK self-sufficient in blood products by the end of 1977.

[Paragraph 19.48] *There had already been a political commitment to self-sufficiency, however. In December 1974, Dr David Owen MP, the UK Minister of State for Health, had announced exceptional government funding of £500,000 with the primary aim of making the NHS self-sufficient in blood products for replacement of Factor VIII (the factor missing in haemophilia A and by far the largest proportion of blood products by volume) within two to three years, following recommendations by the World Health Organization (WHO). The WHO reinforced its position in 1975…*

2. The risks were the known incidence of "post-transfusion hepatitis" and the known public health risk of future viruses spreading through the blood supply.

[Paragraph 21.5] ***…****No form of therapy was without risk to the patient. As commented in Chapter 2, Patients at Risk, some risks are inherent in the use of human blood and its components and are always present. Whole blood, fresh and fresh frozen plasma and cryoprecipitate were all associated with risk of transmission of virus infections such as hepatitis.*

3. The Government did not fulfil this commitment, and the Health Service continued to use massive quantities of imported product.

This point is a matter of historical record, and it is covered at length in various parts of the evidence.

The following paragraph is quoted to illustrate the lack of 'joined up thinking' among the civil servants and Health Service officers responsible for implementing the Government's commitment, while the paragraph below shows how the UK Government was still paying lip-service to creating self-sufficiency at the end of 1983.

[Paragraph 19.42] ***….****The Annual Report of the SNBTS for the year ended 31 March 1976 noted that the plant* [*Footnote: The Protein Fractionation Centre – the then new Edinburgh plant for processing whole blood to produce blood products]* *had been designed to accommodate material from England and that staff had been recruited and trained on the basis of shiftworking. But opposition from the trade unions, allied*

with demands relating to terms and conditions of employment which the employers found unacceptable, had made shift-working impracticable. In the result, the PFC could cope with Scottish needs on a day-staff only basis, but the absence of the other shifts decreased cost-effectiveness and precluded acceptance of plasma from south of Scotland.

[Paragraph 12.89] *a letter dated 13 December 1983 written by Lord Glenarthur to John Maples MP set out:*

[T]he Government is committed to making this country self-sufficient in blood products… Meanwhile, in the absence of a satisfactory alternative, we shall be dependent upon imports from the USA for an adequate supply of Factor VIII.

4. From 1979 UK haemophilia patients began to be infected with HIV/AIDS from blood product.

[Paragraph 10.57] *…later published in The Lancet on 3 August 1985.The introduction to the published paper reported as background that the virus HTLV-III/LAV was the most likely cause of AIDS and that tests carried out on stored serum samples from haemophilia patients showed that HTLV-III antibodies were first detectable in the USA in 1978 and in the UK no later than 1979.*

5. From studies done in 1984 and 1986, people treated only with foreign blood product were from 4.5 to 6 times more likely to be infected with HIV/AIDS than those treated only with UK blood product.

[Paragraph 10.78] *The source of infection in patients with coagulation defects continued to be debated. In discussion at the meeting on 7 February **[1986]**, Professor Tedder reported that, tests of stored **[blood]** samples dating from 1978 to 1984 showed that seropositivity **[for HIV]** rose rapidly from 33% in 1980 to 64% in 1982 in the case of patients who had received commercial concentrates. In the case of patients who had received NHS concentrates, samples were seronegative until 1982. Between 1983 and 1984 seropositivity rose from 1% to 11%.*

[Paragraph 10.83] *Dr Peter Jones, Director of the Newcastle Haemophilia Centre, also spoke specifically about the incidence in patients with haemophilia: **[in February1986]** he estimated, extrapolating from the limited data available, that 1200 UK haemophilia patients would already have seroconverted. In relation to treatment, he said that of those who had been treated with cryoprecipitate only, 1%*

tested positive for the virus; of those treated with NHS concentrate only, 10% were positive; and of those treated with commercial concentrate only, 45% had tested positive. His basic data were not consistent with the data collected by Dr Rizza and Miss Spooner but referred to a cohort of similar size and with less variance than the data reported by Dr Foster.

6. Some 900 UK haemophilia patients, the vast majority with haemophilia A, have died from AIDS. A proper statistical analysis would be needed to estimate the deaths expected had all treatment been with UK products, but assuming that the ratios above of relative risk were accurate, then on the simple and high-level analysis below only around 200 to 400 would have died.

In line with the indicative evidence of the Report, we assume 50% of patients received UK product consistently and 50% received foreign product consistently. Then, because of the higher infectivity of the foreign product, the 900 deaths would have arisen as:

Risk ratio foreign to UK	4.5	6
Deaths from UK product	164	129
Deaths from foreign product	736	771
Total deaths	900	900

If the Government had achieved self-sufficiency before 1979, all patients would have received UK products and the deaths in the two 50% cohorts would have been the same as in the UK-product cohort in the table above:

Switch all to UK product		
Risk ratio foreign to UK	4.5	6
Deaths from UK product	164	129
Deaths from UK product	164	129
Total deaths	327	257
Lives saved	**573**	**643**

We have widened the range of 257 to 327 deaths to a range of 200 to 400 accommodate the more complex situation which would have pertained in real life,

together with lack of detailed information on people with disorders other than haemophilia A.

7. **Thus the Government failure to deliver its own commitment directly caused the death of some 500 to 700 haemophilia patients through AIDS.**

Our arithmetic model based squarely on the Inquiry evidence bears out this claim. We would welcome independent expert analysis to validate and refine our estimate."

569. This is the end of "Other matters A".

570. Other matters B
I wish to draw the Inquiry's attention to two further recommendations made by the Society in the same response to the Penrose Report, which again are based solidly on the evidence published in the report itself. These related to the systemic failure of public health structures, which led to known risks being allowed to persist without the imposition of known proportionate mitigation. Although these recommendations were written in 2015 with reference to events in the 1970s and 1980s, they have attained even greater urgency in the light of the failure of UK public heath structures to take proportionate mitigating actions to prepare for the known risk of a virus pandemic in the years before 2020.

571. I believe strongly that this demonstrates that the claim of successive governments to have taken all necessary steps to rectify the shortcomings which led to Contaminated Blood is simply untrue, and that after more than 30 years the systemic failures in public health which contributed to the infections and deaths of thousands persist.

572. These recommendations are relevant to the Inquiry's Terms of Reference 10: ToR 10 responsibilities. "To identify, in relation to the matters set out above, any individual responsibilities as well as organisational and systemic failures."

573. Recommendation 2 of the Society's Response to Penrose
That the Governments clarifies how it implements protection of public health across the UK through the current mix of central, local, and devolved Departments and Agencies. The clarification should document clear lines of authority and responsibility, demonstrating that the Governments maintains ultimate responsibility

for public health and has the authority and capability to take decisive action as needed.

The documentation should demonstrate structures of governance and reporting able to ensure that effective systems are in place to protect public health against known and emergent hazards, and also that there is appropriate contingency planning and adequate resources to enable corrective action in the event of emergencies across the UK.

It is unclear to the Society what the UK chain of responsibility is today, and indeed, given that the English NHS and Public Health England are now Agencies, whether the Secretary of State for Health has **any** responsibility for their actions.

574. Recommendation 3 of the Society's Response to Penrose
That the Government commissions an independent report at least every three years which compares the implementation of public health across the UK with international norms from comparable developed countries, and reports an evaluation, an assessment of risks, and recommendations for corrective actions as appropriate, such report to be published promptly and unredacted without intervention by the Civil Service or any Government agency.

575. Such a report in the 1970s would presumably have highlighted the taking of blood donations from high-risk group such as intra-venous drug users and prisoners, together with the risk from a future epidemic leading to as-yet-unknown or uncommon pathogens in the blood supply.

576. This is the end of "Other matters B".

Statement of Truth

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

Signed GRO-C

Dated 13 May 2021