Witness Name: Roderick Morrison
Statement No: WITN5252001
Exhibits:
Dated: 3rd May, 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF RODERICK MORRISON

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

I, Roderick Morrison, will say as follows: -

Section 1: Introduction

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

1. Name: Roderick (Roddy) George Donald Morrison

2. Address: GRO-C, Manchester GRO-C

3. Date of Birth: GRO-C 1969

4. Professional Qualifications: Associate of Chartered Institute of Bankers, PRINCE 2 Practitioner and MSP Practitioner (Change Management qualifications).

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.

5. Employment History: My career has been focused on delivering change projects in Financial Services companies. This was initially as a full time employee and more recently as a consultant trading through a Limited Company. I've attached my CV for details [**Exhibit WITN525002**].

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

6. Trustee of Haemophilia Society June 2001 – October 2007.

7. Chair of Haemophilia Society June 2003 – October 2007.

8. Co-Chair Haemophilia Alliance 2008 – 2011

9. The questions do not cover this, but I think that it is relevant to state that I have severe haemophilia myself. I was infected with hepatitis B as a child and then C but was one of the lucky few that cleared the virus at the acute stage.

10. I was not actively involved with the Haemophilia Society (locally or nationally) in my youth or early adulthood apart from benefitting from adventure type activities. I was lucky enough to attend an excellent activity holiday in Anglesey and then undertake a climbing expedition to the Pyrenees.

11. My haematology consultant in Manchester (Professor Charles Hay) suggested that I might want to get involved with the Society after I fought a successful battle to stay on recombinant treatment and prophylaxis when I moved from London to Manchester in 1995. Despite being in full time employment and having 2 young children at the time, I was initially offered a return to on demand treatment and intermediate purity concentrate which would have caused certain damage to my joints, curtailed my career and risked further infections.

12. It was a privilege to be first a Trustee and then Chair of the Society and to be able to present the Society's submission to the Archer Inquiry.

13. Since the Archer Inquiry and following a spell as co-chair of the Haemophilia Alliance I have stepped back from involvement with the Society. I have had no meaningful involvement since then and my evidence is therefore effectively limited to the period 2001 until 2011.

14. Other than copies of the Society's first submission to the Archer Inquiry and a copy of the Archer Inquiry Report I have not retained papers from my time as a Trustee or as Chair. I therefore do not have the Trustee Board papers for example and this hindered my ability to answer some of the questions. I am grateful for the additional papers provided to me in both January and March 2021 which have allowed me to update this statement in part.

15. I reference the Society's Submission to the Archer Inquiry a lot in my answers. It represents a comprehensive summary of the information available to me in my time as Chair of the Society.

Section 2: Previous Evidence

Q4. Please consider the evidence which you gave to the Archer Inquiry. Please confirm whether your evidence to the Archer Inquiry is true and accurate. If there are any matters contained within your oral evidence to the Archer Inquiry [ARCH0000005, pages 77 - 95; and ARCH0000010, pages 29-67] that you do not consider to be true and accurate, please explain what they are.

16. I can confirm that the Haemophilia Society's evidence to the Archer Inquiry (that I presented) was true and accurate to the best of my knowledge.

17. The submission was collated by members of the staff team with input from many members and groups. It is fully referenced.

18. I reviewed and approved the submission. I wrote the summary of the submissions that I presented on the 4th June and 30th August 2007.

19. I note now (March 2021) that you have copies of the full Submissions the Haemophilia Society presented. I initially reviewed the transcripts in Egress, but these of course just reflect the verbal presentations and discussion.

20. I hope that you have full access to all the evidence provided including both of the Society's submissions. I only have a hard copy of the initial Submission now but I'm sure that the Society will have provided you with a copy of all documentation.

Q5. 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.

21. The only Inquiry that I have provided evidence to or been involved in is the Archer Inquiry. I have not been involved in any litigation.

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

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

22. The objectives and functions of the Society were quite stable throughout my time as a Trustee and then as Chair.

23. These were stated each year in the Trustees Report section of the Annual Report and Financial Statements and updated in line with strategic reviews that were undertaken periodically. They were extended in 2007 to specifically include 'related bleeding disorders'.

24. I have looked back at these Reports for the period of my involvement and although the description of objectives and function evolved somewhat over that time the best summary is still per the submission to the Archer Inquiry (page 3):

> 'The Haemophilia Society is a charity which works for people with haemophilia, von Willebrand's and related bleeding disorders and their families. Our objectives are to relieve the suffering of people with haemophilia and improve education into the nature and causes of haemophilia.
>
> We aim to secure the best possible care, treatment and support for people with these conditions. We work to assist people with haemophilia and related disorders by providing information and support, by representing the interests of people with haemophilia and related bleeding disorders and amongst the public and with health professionals.'

25. In my time as a Trustee from 2001 to 2003 there was a strong focus on developing and providing support services for those infected with HIV and HCV. There was also a significant focus on campaigning (for recompense for those infected by HCV and for recombinant treatment for all). The All Party Parliamentary Group was established and the Haemophilia Alliance (co-chaired by the Society) published a National Service Specification.

26. In my time as Chair from 2003 until 2007 we conducted regular needs assessments and reviews of the services the Society should provide. Alongside our focus on specialist support for those infected by HIV and HCV and advocacy and campaigning we sought to strengthen the services we provided in newer areas that reflected evolving needs in our communities. These included:
    - Youth work (including HQ Too magazine and then dedicated youngbloods magazine and website)
    - Women and Bleeding Disorders (including Female Factors magazine and then the Women Bleed Too Project)
    - Inhibitor Support Group
    - Support for a growing community of over 50s (including the Health and Independence Project)
    - A refreshed focus on research including a Research Advisory Panel
    - A move to free membership which saw a big rise in membership.

Q7. Please confirm the dates of your roles at the Society and explain what your responsibilities were in relation to each role and how your role and responsibilities changed over time. In your answer, please describe your role and responsibilities with regards to the Society's publications.

27. I was a trustee of the Haemophilia Society from 23rd June 2001 until 6th October 2007.

28. I was Chair of the Board of Trustees of the Haemophilia Society from 23rd June 2003 until 6th October 2007.

29. The responsibilities of the Trustee role were summarised in the Trustees Report annually which also confirmed that the Trustees are directors for Companies Act purposes. The Society had a good Trustee induction process when I joined and throughout my time there.

30. Trustee responsibilities are stated in HSOC0020158 - Report and Financial Statements for the Year Ended 31 December 2002. Later Annual Reports contained a full summary of the Trustee Induction Process (Year Ended 31 December 2006 is an example). These reports are all freely available.

31. Please let me know if you'd like further detail on this.

32. During my time as a Trustee I was also a member of the Resources Sub Committee (due to my background in financial services). When I became Chair, I chaired the Trustee Board meetings and became the primary contact for the CEO.

33. Specifically, in terms of publications, I approved the Trustees Report each year that I was Chair and periodically contributed to other publications.

Q8. 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.

34. The structure of the Society including the governance and day to day management are covered in the Annual Report and Financial Statements. Year Ended 31 December 2006 summarises the position when I was Chair well.

35. In summary:
    - There was a Trustee Board of 12 (10 directly elected by the membership and up to 2 co-optees if specific skills were lacking but required)
    - The Trustee Board appoints from within its members a Chair, Treasurer and up to 2 Vice-Chairs
    - The Trustee Board appoints a Chief Executive and delegate day to day management to that person
    - The Chief Executive reports on a regular basis to the Trustee Board and is directly accountable through the Chair
    - There were a number of restructures during my tenure – aimed at reducing operational costs when budgets were under pressure and ensuring a focus on service provision. These took place in:
        - 2003 (predominantly to balance the budget)
        - 2004 (to align to an updated development plan following a member and staff consultation)
        - 2007 (like 2003, predominantly to balance the budget).
    - Details are in the relevant Annual Report and Financial Statement.

Q9. Please describe the relationship between the Board of Trustees, Council, Executive Committee and the day-to-day management of the Society.

36. I don't recognise the terms 'Council' or 'Executive Committee'.

37. Day to day management rested with the Chief Executive who reported to the Trustee Board (6 meetings per year). A written progress report including any decisions required was presented to the Board

38. When I was Chair, I would also have regular one to one conversations with the Chief Executive to monitor progress and offer support.

Q10. Please explain the dynamics and hierarchy of the staff and trustees at the Society. Please include (a) the formal and informal line management arrangements, (b) the decision-making structures and (c) whether any staff or trustee had particular influence over decisions of the Society.

39. (a) In a strict sense the reporting structure and operational hierarchy was very straightforward. Each member of staff reported either directly or through a line manager to the Chief Executive. The Chief Executive reported to the Board of Trustees and was accountable to the Chair. There was also a published set of guidelines for volunteers who undertook a lot of the Society's work.

40. (b) The decision-making structure was again straight forward with papers presented to Trustee Board for decisions with ad-hoc management within the remit of the Chief Executive.

41. (c) The dynamics of engagement between the staff and trustees will have varied over time as circumstances and individual characteristics changed. The Chair and Chief Executive would have had a natural influence. My role as Chair included ensuring that the voices of all Trustees were heard. I would not say that any member of staff or trustee had a particular influence whilst I was Chair although I would be keen to ensure that key voices were heard on certain topics (including for example Phil Dolan and GRO-D on both campaigning and devolved issues).

Q11. 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?

42. I worked with 5 Chief Executives in my time as Chair (clearly more than was ideal).

43. The working relationship was naturally different with each person, but I would characterise as generally close and collaborative.

44. Their role was day to day leadership of the Society to deliver against the agreed objectives, plan and budget. My role was to hold them to account for this and to support them in their role.

45. I had regular meetings with each Chief Executive but tried not to interfere at a detailed level. We would agree agendas for Trustee Boards and often work together to review options and look at strategy.

Q12. What methods (if any) did you use to report the Haemophilia Society's activities to the Executive Committee and/or Board of Trustees?

46. The reporting to the Board of Trustees was by the Chief Executive. I would introduce and chair Trustee Board meetings, highlighting the key decisions required, the allocation of time to discussions and would work to establish clarity and consensus on each decision.

3.1 Committees and Advisory Bodies

Q13. 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. Please include a description of the Treatment and Care Committee and the General Services Committee. Please include a description of the Policy Committee, Services Committee, the Finance Committee, the Blood Products Task Group, the Health Sub-Committee and the Information and Communication Sub-Committee and the extent and period of your involvement.

47. Again, there are terms here that I don't recognise – Treatment and Care Committee, General Service Committee, Policy Committee, Services Committee, Finance Committee or the Blood Products Task Group. Perhaps these were before my time?

48. When I became Chair there were 3 sub committees and 1 advisory panel:

49. <u>Resources Sub Committee</u>
    - Chaired by the Treasurer (a member of the Trustee Board)
    - Reviewed management accounts and held the Finance Officer and Chief Executive to account on performance against budget etc.
    - Reported to the Trustee Board
    - I attended this as both Trustee and then Chair.

50. <u>Health Sub Committee</u>
    - Chaired by a Vice-Chair (a member of the Trustee Board)
    - Attended by co-opted members of the medical community
    - Reported to Trustee Board
    - I did not attend this as either Trustee (my focus was on Resources) or as Chair (combination of lack of time and because other trustees had more relevant experience and interest).

51. <u>Information and Communications Sub Committee</u>
    - Chaired by a Vice-Chair (a member of the Trustee Board)
    - Met on an ad hoc basis

- My understanding is that this was an active committee when I was a Trustee, especially in respect of the campaign and PR activity
- It met increasingly infrequently over time and eventually ceased to be.

52. Medical Advisory Panel
    - A range of medical advisors (covering Haematology, Nursing, Hepatology, Orthopaedics and Physiotherapy) who were available to provide advice periodically as required.

53. In my time as Chair 2 further Advisory Panels were established:

54. Women Bleed Too Project Board
    - Established to govern the Women Bleed Too Project
    - Representation from medical and patient communities
    - Patient representation was both from within and outside the Trustee Board.

55. Research Advisory Panel
    - Established to invite research proposals in line with priorities established by the Trustee Board
    - Make recommendations to the Trustee Board on what proposals to fund
    - Monitor progress on commissioned research
    - Representation from medical and patient communities (again both Trustees and non-Trustees).

56. Latterly and specifically in the approach to the Archer Inquiry a Campaign Group was established – see Section 7.1.

57. The National Haemophilia Alliance is covered in Section 3.3.

Q14. In the Minutes of Trustees meeting held on 20 November 2002 you expressed a desire to be part of a strategic planning group [HSOC0029689_047]. Was this group formed? If so, please describe its purpose, functions, responsibilities, and the extent and period of your involvement.

58. I assume that the strategic planning group met before the Resources Sub Committee on 21st February 2003 (per HSOC0029689_047) but I cannot say so definitively I'm afraid. I'd assume that it would have been documented as part of the Resource Sub Committee minutes and I'd assume these are available to you.

59. The Annual Report and Financial Statement for year ended 31st December 2003 includes a section on Strategy and Planning. This states that trustees and staff had reviewed marketing, fundraising, membership and IT strategies as well as service provision in light of a needs assessment survey in 2003. This was to be used to form 3 – 5 year plans for consultation in 2004.

Q15. To the best of your knowledge, please list all the committees, "task groups" and/or advisory bodies that the Haemophilia Society's Executive Committee, Trustees and staff relied on for medical advice and opinions on the safety of blood products

and/or the risks of transmission of HIV, hepatitis, and vCJD. Please include, where possible, details on the extent to which (if any) they were staffed by members of the Haemophilia Society, external advisors, pharmaceutical representatives and/or clinicians.

Q16. Further to the above, please detail your role and/or involvement with the above mentioned sub-committees, 'task groups' and/or advisory bodies.

60. To the best of my knowledge any such advice and opinions would have been through the Medical Advisory Panel and / or the Health Sub Committee. These would in turn have reported to the Trustee Board.

61. The current members of both of these groups are listed in the Annual Report and Financial Statement each year. These were medical advisors, staff and trustees.

62. I did not attend the Health Sub Committee and to the best of my knowledge my engagement would have been through papers tabled at the Trustee Board. This will be evidenced by agendas, papers and minutes of the Trustee Board.

3.2 Interaction with Other Organisations

Q17. Please detail the nature of the relationship between the Haemophilia Society and other similar organisations, including campaign groups, such as the Manor House Group and Tainted Blood.

63. This is a very interesting question. I don't think that you could easily, precisely or consistently define the relationship between the Haemophilia Society and other organisations including the Manor House Group and Tainted Blood. These relationships were about people and therefore changed as personalities changed, certainly at the Society.

64. I would say that when I joined as a Trustee, I was unaware of the number of different groups within the Haemophilia community. I was also naive as I didn't appreciate how the pain and suffering over so many years had led to different groups being established. I learned that not all members of our community had a consistently positive view of the Society.

65. As Chair, I tried to build stronger relationships with other groups, especially campaign groups and individuals. That was a large driver for establishing the Campaign Group.

Q18. Did the Society help to promote the aims and objectives of other similar organisations?

66. I don't believe that in my time as Chair the Society actively promoted the aims and objectives of other similar organisations.

Q19. Did the Society speak out against the aims and objectives of other similar organisations?

67. More importantly in my view and to the best of my knowledge we certainly did not speak out against the aims or objectives of other similar organisations. That would certainly never have happened with my knowledge or approval.

Q20. Was there any overlap between those holding roles within the Haemophilia Society, and those holding roles within other similar organisations?

68. There were times when there was overlap and an individual could hold a role in the Society and in another organisation.

69. The one example I remember clearly was GRO-D. GRO-D (an inspirational campaigner and wonderful colleague now sadly passed) for a time was both a Society Trustee and a leading member of Tainted Blood. I'm not sure that this would always have been a workable arrangement previously.

70. From memory, GRO-D completed a conflict of interest form and he became adept at wearing both a Society and a Tainted Blood hat. He was clear as to which hat he was wearing when. GRO-D and I always had clear conversations about this.

Q21. Please describe the relationship between the Society and the UK Haemophilia Centre Directors Organisation ("UKHCDO"). What interactions took place between the two organisations? How did this develop over time? Did you encounter any difficulties in this relationship?

71. To the best of my knowledge the relationship between the Society and the UKHCDO directly was predominately between the Society's Chief Executive and the UKHCDO's chair. I believe that there were periodic informal conversations between the two.

72. This is distinct from the Haemophilia Alliance (see Section 3.3 below).

Q22. What was your role and involvement with the UKHCDO? Did the Society's committee members attend the Regional Meetings of UK Haemophilia Centre Directors? If so, what was the function and purpose of the Haemophilia Society's committee members attending the Regional Meetings of UK Haemophilia Centre Directors?

73. I did not have a role and involvement with the UKHCDO directly either as Trustee or Chair. I do not know if Society committee members attended Regional Meetings of the UKHCDs I'm afraid.

Q23. What was the relationship between the Society and Haemophilia Action UK? What interactions took place between the two organisations? How did this develop over time? [HSOC0028407 may be of assistance].

74. I don't have a strong recollection of any particular relationship between the Society and Haemophilia Action UK. I do know that I grew to have a tremendous respect for the campaigners involved with Haemophilia Action UK.

75. I would say that relationship grew closer over time, largely as a result of the efforts of GRO-D and through our Campaign Group.

76. I've re-read the emails in HSOC0028407 with some sadness. I was Chair at the time of those emails and was undoubtedly still finding my feet in terms of the wider campaigning community and the different groups.

77. I don't remember the specifics of the concerns expressed but do understand and remember the difficulty involved in the Society striking a balanced and factual tone.

78. I do know that the relationship grew closer through conversation and engagement over time.

Q24. Please describe the relationship between the Society and the Haemophilia Society Scotland? What interactions took place between the two organisations? How did this develop over time? Please include a description of any strategic or conceptual disagreements that the two bodies had.

79. I don't have strong memories of how we worked with Haemophilia Scotland in my time as Chair. It was still a Voluntary Association I believe. It was then established as a Scottish Charity in 2012.

80. I am familiar with it of course as former Society Trustee colleague and inspiring campaigner Philip Dolan played a leading role in its establishment. Another former Society staff colleague Dan Farthing (who played a strong role in producing the Society's submission to the Archer Inquiry) became the Chief Executive.

81. Philip was a Society Trustee for most of my time as both a Trustee and Chair including in 2004 and therefore, he wore two hats at times.

82. I do recollect that the relationship between the Society and Haemophilia Scotland was not clearly defined when I was Chair. There were local groups of the Society in Scotland including in my home turf of Grampian. Haemophilia Scotland certainly was not positioned as a local group however (the very idea would have made Philip indignant with rage!). I've read further now and perhaps with hindsight there wasn't a clear relationship until Haemophilia Scotland was established as Charity in its own right and a Memorandum of Understanding with the Society agreed.

83. I think it would be fair to say that in 2004 we were muddling through, certainly I was.

Q25. Please provide a description of the Scottish Advisory Group. Please include why it was created, who were its members, what was its purpose, and when it ran from and to. [You may be assisted by HSOC0020087]:

a. In a letter to you from Philip Dolan dated 1 May 2004 regarding the Scottish Advisory Group he references a "Project". Please describe what this project was and when it ran from and to.

b. In the above document, Philip Dolan writes that "as one of the signatures to the Project I now feel that I should advise the Community Fund that we have wasted public money." What was your response to this comment?

84. The Scottish Advisory Group was created in 2002. I remember the project that was established, Philip's email and many subsequent conversations.

85. The best summary of this is within the Annual Report and Financial Statement to 31st December 2002 (HSOC0020158):

'Scotland

The appointment of a new development worker for Scotland in April 2002 was a milestone in the project supported by the Community Fund (Scotland) and Scottish Executive to enable the Society to meet the needs of people with haemophilia and von Willebrand's north of the border. Much progress was made in the year including the development of a needs assessment questionnaire, which will be distributed to all people with haemophilia and von Willebrand's in Scotland and via haemophilia centres and our own membership database, the setting up of a website and launch of a newsletter for Scotland. The project is overseen by a Scottish advisory group of affected people and interested professionals.'

86. The Annual Report the following year, to 31st December 2003 again mentioned the project but alluded to difficulties relating to accommodation and staff sickness.

87. The funding from the Scottish Executive ran until 2004 and the Project would have closed at this time and I think the Advisory Group would have ceased at that time too.

88. I cannot recall all the members of the Advisory Group I'm afraid, but the Society should retain this information and there would have been regular updates to the Trustee Board within the Board papers.

89. On the further points raised:
    a. The 2 year project is as described above.
    b. My response to Philip's view was that the management and the performance of the project had to be improved and we needed help from all to achieve that.

90. I believe that the project concluded having only partially met its objectives and the Society had learned 2 salutary lessons:
    a. The difficulty in trying to control an outreach project remotely from a London office – far better to delegate it properly to be managed locally

b. The need for collaborative dialogue between 'Head Office' and bodies such as the Advisory Group.

Q26. In the Three Year Strategy section of the 2003 Report to Trustees [HSOC0020104], it was agreed that you would take forward the exploration of devolution. What conclusions did you reach? Did these conclusions impact how the Society was run or organised? If yes, please give a detailed account of any changes.

91. I don't believe that the exploration of devolution went beyond further discussion with Trustees and at subsequent Away Days. Certainly, it was not prioritised into operational plans and therefore had no substantive impact on how the Society was run or organised.

92. As seen in Question 25, Haemophilia Scotland was formed but this was not as part of pro-active work by the Society.

Q27. Please provide details on the efforts of the Society to help obtain a Scottish Inquiry. Were these efforts performed in collaboration with the Haemophilia Society Scotland? [You may wish to refer to HSOC0013857 and HSOC0023072, page 12 to assist you.]

93. The work to obtain a Scottish Inquiry was starting to bear fruit as my time as Chair came to an end.

94. My memory of this isn't detailed but my recollection is that the Society's role was a reactive one of support with the campaigning being led by Scottish campaigners and Haemophilia Scotland. Philip Dolan played an absolutely critical role.

95. The Society – and I – were really focused on The Archer Inquiry in terms of our campaigning activity.

96. I'm sure that Chris James and Liz Rizzuto will have more substantive value to add on this subject.

3.3. National Haemophilia Alliance

Q28. Please describe the relationship between the Haemophilia Society and the National Haemophilia Alliance, including:

a. Why the National Haemophilia Alliance was formed, including any particular events which prompted it;

b. The aims of the National Haemophilia Alliance, and whether those aims changed;

c. Any obstacles the National Haemophilia Alliance faced in achieving those aims;

d. Whether the National Haemophilia Alliance achieved its aims. If so, when the National Haemophilia Alliance achieved its aims. If not, what the result of the National Haemophilia Alliance work was.

97. (a) I am not completely sure when exactly the Haemophilia Alliance was formed. The Annual Report and Financial Statement for the Year Ended 31 December 2002 has the following commentary on it:

> 'The Society continued to play an active role in the multi-agency alliance ***aimed at improving standards of treatment and care in haemophilia***. This involved a well-attended launch event in February, following which plans were developed for regional 'road shows' to take the national service specification out to commissioners in 2003.'

98. There is more commentary than this, but it suggests that the Alliance was formed around 2002.

99. It is an example of the medical and patient community working effectively together to drive consistency and improvement in care and treatment. It was co-chaired by a member of the UKHCDO and a member of the Society.

100. I am not sure what drove the development of the National Care Specification (other than an obvious memory that there was unequal access to treatment and care nationally).

101. The development and implementation of the national Care Specification was a great achievement (I remember carrying a copy of it everywhere for a time) and its maintenance and enhancement was a key goal of the Alliance.

102. The Society will hold full records of the Alliance including Terms of Reference, Agendas and Minutes etc. I have some agendas and minutes which I have provided to you.

103. (b) Please see a) above. I don't believe that these changed fundamentally but they would have evolved over time to focus on particular areas of treatment and care and commissioning challenges. The aims were expanded post Archer Inquiry (see 32 below).

104. I don't have a strong memory or detailed understanding of this area, but the obstacles were typically ensuring understanding and then budget provision through whichever commissioning regime applied at the time.

105. (c) This is subjective but I would say that the Alliance met its aims well in these years. The creation and implementation of a National Care Specification was a fabulous achievement and very rare as I understand it in the UK. To do so with the active and leading involvement of the patient group was tremendous.

Q29. Please provide details on the collaboration between the Society and the Haemophilia Alliance, which you referenced in your evidence to the Archer Inquiry [ARCH0000005, page 95]. Please provide details of the work performed and completed as part of this collaboration, and please provide details of the benefits of this collaboration.

106. The collaboration mentioned here is the general work with the Alliance to specify best practice and recommended care and treatment standard for haemophilia. Collaboration between medical experts and patients to define this together.

Q30. How did the Haemophilia Alliance work with the Haemophilia Society to put "flesh on the bones" of the Society's recommendations to the Archer Inquiry? Did it achieve these goals? What were the methods used in attempt to achieve those goals?

107. This is much more specific. This is the work undertaken after the Society's first submission to the Archer Inquiry and before the second submission. The second submission contained the Society's detailed recommendations for the future. The work with the Alliance focused on the recommendations on the provision of care.

108. This was discussed in a meeting of the Alliance on 9th May 2007 (HSOC0027665) and was to be followed up at a further meeting on 22nd June 2006 (which I do not have the details of).

109. The recommendations are within the Society's full second submission and are set out in pages 33 to 39 of the PDF ARCH0000010. They focus on establishing a National Haemophilia Committee on a statutory basis.

110. The Archer Inquiry recommendations are broadly in line with this submission – see The Archer Inquiry Report, Chapter 12, Recommendations 1 to 4.

Q31. Please identify the members from each group who were involved in this intra-group work.

111. The Alliance Meeting on 9th May 2007 was attended by Chris Hodgson, Dan Farthing, Mark Winter and I, along with GRO-D and GRO-D. This would have been followed up by Dan Farthing and Chris James along with Mark Winter.

Q32. Did the Haemophilia Alliance meet with any member of the Department of Health? If so, who did they meet with and what items were discussed at these meetings? How were topics decided upon to raise at these meetings? How many of the issues were those raised by members of the Haemophilia Society? Were minutes taken? How did the Department of Health respond to the issues which were raised? Were any assurances made? If so, did any such assurances affect the actions taken by the Haemophilia Society?

Updated questions: Could you please expand on your response provided in relation to question 32 regarding the meetings between National Haemophilia Alliance and the Department of Health, specifically:
a. What matters were discussed? And how did the Department of Health respond?
b. Were the desired outcomes achieved? If not, please provide your understanding as to why this did not happen.

112. I have incomplete knowledge here. Prior to becoming directly involved with the Alliance (see 33 below) my knowledge would have been limited to papers presented at Trustee Boards. Per my comments above the Society will hold any relevant records. I have read the papers shared with me in March which include the minutes of a number of Alliance meetings

113. When I was Co-Chair of the Alliance, we had meetings with the Department of Health to first establish and then run 6 monthly joint meetings. This was in line with the Archer recommendation to establish a National Haemophilia Committee. The DoH refused to put this on a statutory basis but we (the Alliance) treated it as such.

114. I have reviewed all the material I have relating to these joint Haemophilia Alliance and Department of Health Meetings and have provided all of this information to you.

115. The Department of Health proposed agendas and a Terms of Reference for these meetings. All such material would be reviewed and commented on by the Alliance and by the Society, through the Alliance.

116. The Society via its Trustee Board and through the CEO and Communications Manager would ask its representatives on the Alliance to raise any relevant matters in Alliance meetings (e.g. inconsistency in care standards) that had been raised either directly by members or by volunteers, staff, Health Sub Committee or trustees.

117. Specifically, in relation to the establishment and running of these early meetings with the Department of Health, those of us on the Alliance from the Haemophilia Society would discuss (by email, phone and through meetings) priority matters to be raised and desired outcomes of the meetings. These would then be shared with the co-chair of the Alliance from UKHCDO and common agendas and desired outcomes would be agreed

118. In relation to the updated questions from March, I have attached all the material I have which are in relation to the first 6 of these meetings. These indicate the matters raised and the actions resulting.

119. I was only personally involved in the first 2 meetings. My recollection is that some worthwhile traction and progress was made but the standing of the group (i.e. not on a statutory basis) necessarily limited that.

Q33. The Inquiry is aware that after you stepped down as Chairman of the Haemophilia Society, you joined the Haemophilia Alliance [HSOC0019926_005]. Was there an overlap in personnel between the Society and the Haemophilia Alliance? Did people often join the Haemophilia Alliance after leaving the Haemophilia Society, and vice versa?

120. The Haemophilia Society Chief Executive attended the Alliance meetings and the Alliance was co-chaired by a Society representative. I'm not sure that constitutes 'often' but there are 3 clear examples.

121. I took over as co-chair of the Alliance from Chris Hodgson, my predecessor as Chair of the Society. It made sense for the co-chair to be someone with good current knowledge of the Society and therefore a former Trustee or Chair would be an obvious candidate. Liz Rizzuto took over from me.

122. I don't think that it would work the other way around (joining the Society after leaving the Alliance) but the Society would be able to answer (perhaps common or later membership of Alliance and Society Medical Advisory Group?).

Q34. How were you appointed to the Haemophilia Alliance? Did you keep a relationship with the Society while you were part of the Haemophilia Alliance? Did you influence any policies of the Society via this relationship?

123. I was appointed by the recommendation of the Trustee Board (HSOC0019926_005). I was asked and I accepted, I don't believe that anyone else expressed an interest.

124. I didn't have a formal role with the Society whilst co-chair of the Alliance other than as a member. I only took on the co-chair role when I ceased to be Chair of the Society.

125. I kept in regular touch with the Society (predominantly Chris James and Dan Farthing) as the key goal for me at the Alliance was to implement the Archer Inquiry recommendation on working with the Department of Health (see 32 above).

126. I would characterise this as working to implement the goals of the Society through the Alliance. I didn't influence the policies of the Society – it worked the other way around.

Section 4: Knowledge of Risk

Q35 When you joined the Society:

a. What was your understanding of the risks of the transmission of infections generally from blood and blood products? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

b. What did you know and understand about the risks of the transmission of vCJD from blood and blood products? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

c. What did you know and understand about the risks of the transmission of other diseases from blood and blood products by others within the Society?

What were the sources of your knowledge? How did your knowledge and understanding develop over time?

127. (a) I think I joined the Society only when I was asked to think about becoming a Trustee, so I'll answer the question in that way (i.e. my understanding circa 2001).

128. My understanding was that of a typically informed patient from a patient group who had been decimated by the transmission of infections from blood and blood products.

129. I had been personally affected but only in a minimal way. Actually, it is reflective of the issues faced by our community that I view this as minimal – I missed nearly a year of junior school due to Hepatitis B and was lucky enough to clear Hepatitis C naturally.

130. I'd say that all haemophiliacs of around my age and older had an acute knowledge of the risks of infection and how they arose due to our exposure to risk and the experiences of our community.

131. The sources of my knowledge were my clinicians (to a point), information produced by the Society and my own checking of other resources.

132. My knowledge had sharpened when the Trust in Manchester threatened to move me onto 'intermediate purity' F VIII when I moved from London where I had been lucky enough to have been on a recombinant trial.

133. My knowledge grew a lot and was maintained once I joined the Society as a Trustee. It was of course a constant focus of our work (the risk of infection, the impact of infection and the treatment and care required as a result of infection).

134. (b) My memory here is less clear than I would like. vCJD impacted during my time as Chair and I was involved in press interviews about it.

135. I don't think I would have had any understanding of vCJD in 2001 (perhaps a minimal one) and our risk as a community was highlighted completely without warning when patients received letters from our Haemophilia Centres in 2004.

136. My knowledge and understanding grew in line with our reaction to that live incident. The Trustee Board papers from 2001, 2003 and 2004 provided to me in January 2021 give a small commentary on updates on the issue. In 2001 there are references to Society staff members attending vCJD Panel discussions and in 2004 to a meeting between the Society's CEO and Lord Warner and the HPA.

137. I think, therefore, that the Society's approach was to attend briefings when available and then to undertake a reactive response following the notification of risk from Haemophilia Centres in 2004.

138. I can't really add to the summary of this on p12 of the first Society submission to the Archer Inquiry.

139. (c) I don't understand this question relative to 35 above. There was a strong understanding and knowledge of this area by both staff and trustee colleagues when I became a Trustee. Generally, this was far superior to my own understanding with great knowledge with other Trustees and the Services team in the Society in particular.

Section 5: Communication and Dissemination of Information by the Society

5.1 Publications

Q36. Please detail the publications that the Society sent out to its membership from 2001 onwards. Please describe the frequency with which each type of publication was disseminated and whether they were all sent out to all members of the Society. If this changed over time please detail when and why. The Inquiry is aware of:

a. The Bulletin;
b. Haemophilia Quarterly ("HQ");
c. Campaign Update; and
d. C Issues.

140. I have limited direct memory of all the publications, but I have checked the Annual Reports from the time I was involved and would highlight the following:

- Y/E 2002 HQ Too started which was for 7 to 12 year olds
- Y/E 2003 HQ reduced from 4 to 3 issues per year
- Y/E 2004 HQ reduced from 3 to 2 issues per year, but 3 issues of shorter HQ News added.
- Y/E 2005 Female Factors added
- Y/E 2007 Youngbloods magazine and website added.

141. I don't have records on how often each was produced and which members they were distributed too but the Society itself should have records of this.

142. This covers regular publications but there were fact sheets and information guides produced and updated as well, both core information and new areas as result of developments, needs or projects.

Q37. To what extent, if any, did haemophilia centre directors and/or clinicians assist in proposing and/or editing and/or selecting material for the Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

143. Again, I don't have specific memories of this. However, it would have worked on the basis broadly of the Society asking for clinician input when required I think.

144. Clinicians would have been welcome to propose content but I do not believe that they would have had any involvement in editing or selecting material.

Q38. To what extent, if any, did representatives of pharmaceutical companies assist in proposing and/or editing and/or selecting material for the Society's publications?

145. A similar response to Question 37 above. My memory is that pharmaceutical companies may have proposed content and sponsored publications for funded projects and the Society may have had input into publications that the pharmaceutical companies produced themselves.

146. Any engagement with the pharmaceuticals would have been in line with our policy for engagement (the Society will have copies of this) and again I do not believe that there would have been any ability for them to edit or select content.

Q39. In relation to each of the publications produced by the Society, please answer the following questions:

a. Please explain how the publications were made available to members and the wider haemophiliac community? What was the Society's knowledge of the extent of each publication's reach within the haemophiliac community?

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

c. Please identify the members and/or committees of the Society responsible for editing and selecting material for each publication.

d. How did the Society select or identify contributors and interview subjects for each publication? Specifically, in relation to its publications which gave medical and/or other similar opinions including those on treatment options and the risk of infection, how were the contributors for such articles identified? What, if any, were the criteria for someone to be able to write an article for each publication?

e. Please identify the members, groups and/or committees of the Society responsible for editing and selecting material for the Bulletin and other Society publications during your tenure. In your answer, please detail your role and the extent of your involvement with other Haemophilia Society's publications.

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

g. Did the Society know of haemophilia clinicians who felt that their views on imported blood products and/or the risks of infection were not being

represented or communicated to members of the Society? Please provide details, identifying clinicians where possible and the issues they raised. Please explain when and how you came to know of these alternate views and, once you were aware of them, what you did about that.

147. I'm unable to answer this in detail I'm afraid - I don't have that information available to me. There would have been information on this included in Trustee Board papers.

148. From memory, publications and guides were distributed to mailing lists, made available via the Society website and helpline. They were also distributed through Haemophilia Centres.

149. My own involvement in the publications was limited to writing small introductions or reports on meetings that I'd attended.

5.2 Other Communication to Members

Q40. Please detail any activities, other than the release of publications, the Society conducted with the purpose of disseminating information to its members during your tenure. If this changed over time please detail when and why.

150. In addition to publications there was a selection of factsheets and guides produced.

151. A number of events for members were also held, such as the AGM and Conference and specific events as well.

152. A summary of these is included in each Annual Report.

Q41. What were the main concerns and issues reported or relayed to the Society? How did you respond to the concerns?

153. There was a range of questions, concerns and issues reported during my time as a Trustee and as Chair. I have reviewed the Trustee Board papers from that period kindly provided to me. I can't really compile a list of discrete topics at a summary level – there were a wide range across campaigning and services.

154. The way in which we worked to be aware of issues reported or relayed included:
    - Service reports to each Trustee Board including themes of issues being raised through the helpline, by letter and email or otherwise
    - Needs Assessment Questionnaires every 2 years
    - Day to day engagement with members and local groups

155. This information was used to inform operational plans. Again, the Society will have records on all of this, and the outputs from Needs Assessments and the operational plans are summarised in the Annual Reports.

Q42. Did the Society receive direct inquiries from the public or members who required advice with regard to the safety of blood products, or 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 Society rely on to enable a response? Please set out specifically, to the best of your knowledge, what advice and/or information the Society had and from whom that had been provided.

156. Direct queries would certainly have been received. I have reviewed the minutes from Trustee Boards provided but would probably have to do deeper into the papers presented at those Boards to answer fully.

157. The queries would have been directed to the Services team, but I really would have to review the papers and guidance available at the time to answer comprehensively. I am of course happy to do that if you would like me to.

Q43. Was communication with Society members impeded, impacted or compromised by relationships with other organisations?

158. I do not believe that communication with members would have been impeded or compromised in this way. It is harder to say that it would not have been impacted in any way, but I am not aware of any specific examples where it was. I'd be happy to give an opinion on any examples.

Q44. 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.

159. I've read PRSE0000851 in full and with interest. The statement referred to in the question relates to a time when I wasn't involved with the Society, even as a member. I can't provide an objective answer or opinion on this statement.

Q45. In relation to vCJD, what information and advice, during your tenure, did the Haemophilia Society provide to members regarding the:

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

b. Health implications of infection? Please detail the method of communication and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how; and

c. Prevalence of "at risk" status amongst haemophiliacs? Please detail the method of communication and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how.

Q46. Considering your answer to question 45, what was the basis for the communications and advice provided by the Haemophilia Society to members? Specifically:

a. To what extent (if at all) were medical professionals relied upon to produce the advice and opinions in these documents?
b. Who provided that advice?
c. Who, and how was it, decided which medical professionals should be approached for any such advice and what advice should be sought?
d. Who, within the Society, sought any such advice and who did the medical professional provide the advice to?
e. What was their advice in relation to each of the communications you have set out in answer to question 45 above?
f. If advice was received, was that advice edited? If so, why, and by whom, was it edited?
g. Please explain whether the Society also received advice from other medical professionals, what that advice was and, if it conflicted with the published advice, why it was not followed.

160. I want to provide a detailed answer to all sections of this question, but I can't without specific reference to material I don't have copies of.

161. I have been given access to the relevant Trustee Board minutes, but these have only provided limited additional insight. There are references, of course, to vCJD at Trustee Board meetings, specifically in 2004. However, these appear to be restricted to updates from meetings attended by staff members. For example, at the Trustee Board meeting on 5th May 2004 in AOB it was noted that John Morris had attended the vCJD Incident Panel.

162. I would still want to review all detailed papers presented to the Trustee board that covered this topic and likewise communications issued at the time. That might enable me to provide a comprehensive response.

163. Even given access to all the information I had access to at the time then I think it would be hard for me to answer Question 46. This would need to be looked at by those on the Health Sub-Committee in particular.

5.3 The Medical Advisory Panel

Q47. Please describe the purpose, function and responsibilities of the Medical Advisory Panel. If this changed over time, please set out this information according to applicable time frames.

Q48. How did the Society select members of the Medical Advisory Panel? What criteria were used, if any? How did membership change over time?

Q49. Please clarify during your tenure:

a. How was advice sought from the Medical Advisory Panel?
b. Who decided when advice would be sought?

c. Was advice sought from all members of the Medical Advisory Panel or only a selection of them? If a selection, how was that selection determined?
d. How were matters discussed by members of the Medical Advisory Panel?
e. Did some members of the Medical Advisory Panel have more influence than other members, and if so, who carried more influence than others?
f. Were matters discussed at times other than the in-person meetings of the Panel?
g. How was advice communicated from the Medical Advisory Panel to the Society?
h. How was the Panel's advice recorded once it was received by the Society?
i. In relation to what issues relevant to the Inquiry's Terms of Reference, did the Society seek the advice of the Medical Advisory Panel and what was the advice provided by the Panel on those issues?

Q50. As far you can recall, please describe:
a. The extent to which the Society relied on its own judgement when deciding whether or not to formulate policy on the basis of the Medical Advisory Panel's advice;
b. All examples, relevant to the Inquiry's Terms of Reference, of when the Society did not follow the Medical Advisory Panel's advice;
c. All examples, relevant to the Inquiry's Terms of Reference, of when other members of the Medical Advisory Panel disagreed with the advice of the Chair of the Panel;
d. All examples, relevant to the Inquiry's Terms of Reference, of when the Society did not follow the advice of the Chair of the Medical Advisory Panel.

164. Again, I am afraid that I can't provide detailed responses without access to the Trustee Board papers from my tenure. The Trustee Board minutes are insufficient in this regards, the detailed papers presented would be needed,

165. I would be very happy to review these and answer the questions in detail. Although I didn't personally attend the Health Sub Committee, I would be happy to review these papers too if that would be helpful.

Q51. Please provide detail on the decision to appoint a vCJD specific member to the Medical Advisory Panel, as referred to in [HSOC0019926_007, page 4]. Please provide detail regarding the advice sought from the Medical Advisory Panel specifically in relation to vCJD.

166. I recognise Professor Ironside's name but do not have any detailed recollection of the decision or process to appoint him to the Medical Advisory Panel. Clearly specialist knowledge of vCJD would have been pertinent at this time (2007).

Q52. In your evidence to the Archer Inquiry, you stated that the Society had "learnt to be less deferential to doctors and to take their word at face value..." [ARCH0000005, page 85]. What did you mean by this? What if any specific incidences were you referring to? How and when did the Society come to this conclusion? Who was involved in this learning?

167. This was a general statement and informed by learning and experience over time rather than by specific incidences. The Society's first submission to the Archer Inquiry sets out the overall context for this statement and I can't really add to that.

168. When you are part of a patient community that has not always been adequately informed by its clinical community (for example, of the risks of certain treatments and indeed of the results of tests for infections) then of course that changes your approach to the clinical community.

169. On both a personal level and at the Society I would say that we had to learn to adopt a 'show me don't tell me' approach as a result.

170. I am sure that this endures to this day for those impacted by infection or around at that time. For myself, I enjoy a very positive relationship with the team that cares for me, but I would never take advice on proposed treatment protocol changes without extensive research to verify what is proposed. When trust is breached – individually and as a community – it can never be fully restored.

Section 6: Relationship with the Government

Q53. Please detail the 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?

171. The key points of contact were with:
    - Lord Alf Morris (our long standing President)
    - Michael Connarty MP (Chair of our APPG)

172. The relationship with Lord Morris went back over many years and he had extensive contacts in the Haemophilia Community. The key contact was typically with the Society's Chief Executive but in the run up to and during the Archer Inquiry it was with me as Chair.

173. The APPG was established in 2001 and the key contact was with the Society's Chief Executive.

Q54. Please describe the extent of your role and involvement with regard to the Society's interactions with and representations to the Government.

Q55. If you attended any meetings, please provide a detailed account of your meetings with Government ministers and/or civil servants and/or other representatives of the Government. In particular please set out the following:

a. How often did such meetings take place?
b. Who did you meet with?
c. Were the meetings minuted, and if so by whom?
d. What were the purposes of the meetings?

e. What was discussed at the meetings?

174. I don't believe that I had direct interactions with government, that fell more to the Chief Executive.

Q56. 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.

Q57. 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.

Q58. 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.

175. I don't have any information that lets me answer these questions. I am not aware of specific assurances or action taken as a result during my tenure. I have reviewed the further information made available to me in in January and March but cannot find specific information that guides me to any assurances given.
176. Following the Archer Inquiry, a vCJD Haemophilia Alliance meeting was planned and took place. See Q32. The approach to this meeting, however, was to provide access to experts and information, not to express an opinion on the part of the Society or indeed the Alliance.

6.1 All Party Parliamentary Group

Q59. Please explain the relationship between the Haemophilia Society and the All Party Parliamentary Group ("APPG") as referred to in [ARCH0000005, page 93]. Please explain the extent to which the Haemophilia Society determined the priorities, agenda and /or discussion topics of the Group.

177. The Society worked to establish the APPG and it would have had a Terms of Reference when established which the Society will hold in its records.

178. I did not interact directly with the APPG but as a Trustee Board we would have asked the Chief Executive to raise certain topics with the APPG.

Q60. At page 93 of the transcript of your evidence to the Archer Inquiry [ARCH0000005], you said "...we have worked hard to get an all party parliamentary group in place, which has been tremendously beneficial as well, very, very helpful." Please set out what was achieved by the APPG.

179. The benefit was having regular access to parliamentarians, for them to be aware of what you were trying to achieve and for them to work on your behalf.

180. It was very beneficial in terms of MPs tabling questions and holding ministers to account for their actions.

6.2 Funding

Q61. In the Trustees meeting on 15 March 2006, it was stated that there was an "Over-reliance on Department of Health funding and the pharmaceuticals" [HSOC0019926_001, page 2]. Please detail the removal of the Section 64 funding which the Society faced, and any potential impact this may have had on the funding and budgets of the Society? Was there concern that the Society would need to have a greater reliance on funding from pharmaceutical companies?

181. This comment was part of the Fundraising Manager's presentation of the Fundraising Strategy to the Trustee Board in 2006.

182. There were periodic threats to the Section 64 Funding and from memory in 2006 the Section 64 funding was due to be phased down and then withdrawn in the following years (the accounts to end March 2008 show the first reduction and the Finance papers to Trustee Boards will contain the full detail).

183. The impact on budgets would have meant a loss of a stable funding stream, a stream which was very helpful in terms of having confidence in the ability to fund ongoing provision of core services. Seeing that stream reduce in value or fall away meant having to find additional funding sources which as a small charity had proved difficult to do.

184. Pharmaceutical companies provided an important source of funding too, but the Society was careful about how this was approached and utilised. Loss of Section 64 funding meant having to reduce services or finding new funding, it did not automatically lead to a great reliance on the pharmaceutical companies.

6.3 Availability of Documents

Q62. In your evidence to the Archer Inquiry, you said "We believe the government has been selective about what has been released, although of course we do not know what we do not know." [ARCH0000005, page 83]. Please explain this statement further. Why did you form this view? What was the basis for your view?

185. The full context to this statement is on p35 of the Society's first submission to the Archer Inquiry under the heading Missing Documents.

Section 7: Campaigning

Q63. In the Notes from the Trustees Away Day section of the 2002 Report to Trustees, there is a bullet point that states "Staff perception that campaign dominates trustee board and services seen as less important" [HSOC0020193, page 2]. Please comment on the accuracy of this perception.

186. I don't think it is for one individual to challenge the perception of a group – their perception was their honest assessment of the position.

187. My opinion is that the campaign did take up a lot of trustee board time in 2002. Because the infected blood disaster had never been properly investigated then the campaign had to be an inevitable focus of the Society and rightly so. At the same time, there was a tremendous need for both service provision to those infected and also for service extension to other groups including the young and women with bleeding disorders as just 2 examples.

188. The focus of the Board did widen in the following years in line with strategy (see Question 6 above).

Q64. In the transcript of your evidence to the Archer Inquiry on 30 August 2007 [ARCH0000010, page 53], you made reference to 'the campaign group'. Please detail the membership and structure of this group? How did people join the group, and who led the group? [HSOC0003014 may also be of assistance].

Updated questions from March 2021.
In your response to questions 17 and 23, you refer to the Campaign Group. Please can you provide further information regarding the Campaign Group, specifically:
a. Why did the Society set up the Campaign Group; and
b. What, if any, were the challenges faced in setting up the Campaign Group.

189. I remember that the group was less formal than the question implies – it wasn't a sub-committee of the Trustee Board or an Advisory Group.

190. It was established with a desire to have closer working relationships with all campaigners, be they individuals or groups. The invite for the first meeting came from the Society but the importance of the Group was that it was for everyone who attended – it was not driven by a Society agenda or direction.

191. I was very keen for us all to work together as a community and GRO-D played a key role in bringing people together.

192. I believe that the first meeting was on 4th November 2005 and I chaired that meeting, really to try and facilitate the conversation where goals were discussed as was pooling information to help overall campaigning.

Q65. How often did the group meet? How were decisions made about the priorities of the group?

193. I think the group met broadly in line with Trustee Boards. I have reviewed the notes from the meetings of the Campaign Group on 4th November 2005, 2nd May 2006 and 8th May 2007 although that is not the full set of meetings.

194. Decisions would have been made by consensus within the group.

Q66. Please explain what the goals and priorities of the group were.

a. How were the goals set?

b. To what extent, if any, did the campaign group achieve these goals during your tenure? Please detail the actions taken in attempt to achieve these goals.

195. The goals and priorities would have been set by consensus.

196. The meeting on 4th November 2005 discussed the overall objectives for campaigning.

197. However, the key goal was full a Public Inquiry into the Infected Blood disaster.

198. Each campaigner will have their opinion on how the goals were met but we did achieve the Archer Inquiry. Although an independent rather than a Statutory Inquiry this was a great achievement in my opinion.

199. I have reviewed the additional documentation provided in January 2021 and HSOC0021267 shows that the Campaign Group confirmed the outcomes it wanted from the Archer Inquiry at the Campaign Meeting on 8th May, 2007.

7.2 Campaign for a Public Inquiry

Q67. What role did the Haemophilia Society play in seeking a public inquiry? When did the Society consider an inquiry was a possible course of action? Why was that decision made then? Please set out chronologically the Society's campaign and or involvement in the campaign for an inquiry, including any discussions with the Government and any assurances that were received from the Government.

200. I believe that the Society played a leading and strong role in this. This is summarised in Section 3 of the Society's first Submission to the Archer Inquiry. I have little to add to that – I refer to that submission frequently because it sets out the Society's position (and mine) very clearly at a point in time toward the end of my time as Chair.

Q68. In the Minutes of the Board of Trustees meeting held on 1 May 2002, the Trustees agreed that "the Society's campaign for a public inquiry should be put on hold" [HSOC0029689_044]. Why did the Haemophilia Society decide to put on hold the campaign for a public inquiry? What (if any) representations by the government did the Haemophilia Society rely on in this decision? [You may also be assisted by HSOC0029689_042, and HSOC0029689_041].

201. I've read the 3 Trustee Board Minutes (HSOC0029689_41, 42 and 44) with interest.

202. The decision to put the campaign for a public inquiry on hold at that time (although I was not present at the Board meeting that made the decision) was made for the following reasons:

- Concerns about the expenditure on continuing the campaign in the same way (i.e. ongoing expenditure from reserves on Weber Shandwick)
- Prioritisation of the 3 campaign aims (with recombinant and recompense prioritised above public inquiry) informed in part by an assessment of how achievable to goals were seen to be at this time.

203. I am not aware of assurances or representations by the Government that were relied on by the Society in making this decision.

Q69. In the Minutes of the Board of Trustees meeting held on 21 June 2002, the "Trustees agreed that it was important to explain to members that The Society's financial situation requires that the level of resource devoted to the campaign be reduced. Experience indicates that there is little or no hope of winning a public inquiry or recompense for HCV" [HSOC0029689_045]. Why did the Haemophilia Society come to the conclusion that there was "little or no hope of winning a public inquiry or recompense for HCV"? What (if any) assurances and/or representations by the Government did the Haemophilia Society rely on? [You may be assisted also by HSOC0029689_042 and HSOC0029689_041].

204. I can't add to the information summarised in HSOC0029689_045.

205. This conclusion was per the report tabled as part of the Trustee Board papers and the update by the Chief Executive concerning the meeting with Hazel Blears (then the Health Minister).

7.3 Campaign for Recombinant Blood Products

Q70. The Inquiry is aware of the Haemophilia Society's campaign for recombinant blood products. The following document may be of assistance: [MACF0000006_118]. Please explain, giving as much detail as you are able:

a. When and why the society launched the campaign, including any particular events which prompted it;

b. The aims of the campaign;

c. Whether those aims changed and, if so, why;

d. Who was responsible for the campaign;

e. The actions taken by the Haemophilia Society to further the campaign;

f. Any obstacles the Haemophilia Society faced in achieving those aims, including, but not limited to, internal disagreements within the Haemophilia Society;

g. What the response of the Government was to the campaign, including whether the Haemophilia Society was given any assurances by the

Government in relation to the campaign. If so, what the assurances were, when they were given, by whom and whether the assurances caused the Society to change their approach to the campaign.

h. Whether the Haemophilia Society achieved its aims;

i. If so, when the Haemophilia Society achieved its aims;

j. If not, what the result of the campaign was.

206. The campaign for recombinant treatment for all had started before I joined the Society (but was a core reason for me joining as a Trustee).

207. Recombinant became available from 1993, was declared treatment of choice by UKHCDO in 1995 but the campaign to ensure recombinant for all was not won until 2003. Rollout required further campaigning and was not completed until 2006.

208. I would have to review all campaign updates to the Trustee Board to be able to answer all elements of this question in detail I'm afraid.

209. The Annual Report to Year Ended 31st December 2003 confirms that the campaign had been successful in winning a commitment to recombinant for all (in line with the prioritisation of campaign aims highlighted above).

Q71. On 25 February 2003 Chris Hodgson made a complaint (via Lord Morris) to the Parliamentary Ombudsman in relation to possible maladministration as a result of the provision of recombinant products to patients in England [HSOC0012668]. Was a response received? If you are aware of the outcome, please set it out in as much detail as possible.

210. I do not know if a response was received. It would presumably be in the Society's records though if one was.

Q72. How often did a trustee or a member of the Haemophilia Society meet with a representative of the Department of Health on the matter of recombinant products, such as Margaret Unwin did referenced in [HSOC0019926_001, page 3]? Were any assurances made? If so, what if any reliance was placed on those assurances by the Society?

211. I am not aware of how often such meetings took place. They would have been detailed in updates at Trustee Boards.

Q73. How were the strategies for the campaign for recombinant products formulated? Were these strategies always carried out? [You may wish to refer to HSOC0019926_001, page 3 to assist you.]

212. I don't see that HSOC00119926_001 is of help in this regard. The strategies for the recombinant campaign were formulated before my time but continued throughout

until the campaign was won and implementation completed as per question 70. Any perceived threats to this such as we saw in 2006 would have been managed as described in this instance.

Q74. How, if at all, did the Society's relationship with the UKHCDO assist with the campaign for recombinant products?

213. The fact that UKHCDO had declared that recombinant was the treatment of choice was of course very helpful to the campaign.

Q75. It was stated in your evidence to the Archer Inquiry [ARCH0000005, page 86] that "it took a decade of hard campaigning for the haemophilia community to access recombinant treatment for all." Please detail the campaigning efforts of the Society to help to achieve recombinant treatment for all rather than have it be determined by a 'postcode lottery'.

214. I don't have a concise summary of the campaigning efforts I'm afraid but would refer you to p31 of the Society's first Submission to the Archer Inquiry.

7.4 Campaign for Financial Assistance

Q76. The Inquiry is aware of the Haemophilia Society's campaign for financial assistance [HSOC0009365, HSOC0029689_041, HSOC0020158, HSOC0029566_028 and HSOC0003277 may be of assistance]. Please explain giving as much detail as you are able:

a. When and why the society launched the campaign, including any particular events which prompted it;

b. The aims of the campaign;

c. Whether those aims changed and, if so, why;

d. Who was responsible for the campaign;

e. The actions taken by the Haemophilia Society to further the campaign;

f. Any obstacles the Haemophilia Society faced in achieving those aims, including, but not limited to, internal disagreements within the Haemophilia Society;

g. What the response of the Government was to the campaign, including whether the Haemophilia Society was given any assurances by the Government in relation to the campaign. If so, what the assurances were, when they were given, by whom and whether the assurances caused the Society to change their approach to the campaign.

h. Whether the Haemophilia Society achieved its aims;

i. If so, when the Haemophilia Society achieved its aims;

j. If not, what the result of the campaign was.

215. The campaign for financial assistance predates my involvement as a member or trustee of the Society and was initially for HIV infection and subsequently for HCV infection.

216. The documents you have referenced here give a reasonable overview of progress on the HCV campaign through from a launch event in 1998 through to events in 2003 when first the Scottish Health Minister and then the UK Health Secretary announced financial assistance schemes.

217. The AGM, Annual Report and Trustee Board papers referenced reflect the debate about how much effort and expenditure to commit to campaigning at those times.

218. The Society's first submission to the Archer Inquiry and its appendices contain the best summary of the information available to me.

Q77. What involvement, if any, did you have in the preparation of the Report of the Hepatitis C working party [HSOC0005927]? Please explain how the Working Party came into existence and how the report was subsequently utilised in the campaign for recompense.

219. I had no involvement in the Report of the Hepatitis C Working Party. I attended the Trustee Boards at which it was discussed, however.

Q78. At an extraordinary Trustees Meeting on 25 September 2003 the Society's "negotiating position" was agreed [HSOC0020127_001]. How was this communicated to the Government? What response did you receive to those communications? How, if at all, did that response change the position taken by the Society?

220. This would have been communicated to Government through the actions noted at the meeting and taken forward by the Chief Executive.

221. The updates from that would have reported back at Trustee Board meetings. Without being able to check those detailed Board packs I do not specifically remember the response from the Government or how any response changed the Society's position.

Q79. On 12 July 2004 Professor Hay wrote an email to other UKHCDO Directors about your involvement in the Society. Please explain the context for this email. Were you informed that the Directors would be disappointed if the Society "chose to associate itself" with a campaign for recompense? What influence, if any, did this have on the decisions taken by the Society? [HCDO0000254_557]

222. I have read this email with interest, not having seen it before. Professor Hay was and remains my clinician and it was Professor Hay who recommended to me that I should get involved with the Society (per my introductory comments).

223. I do not know the context of the email although it would appear to relate to a letter to Frank Hill – I don't have a copy of this but would be happy to review it if you have access to it through the Society.

224. I don't remember any conversation that included being informed that the Directors would be disappointed if the Society 'chose to associate itself with a campaign for recompense and a public inquiry'. By 2004 the campaign was more about the Public Inquiry than recompense.

225. I believe that Professor Hay and I managed to keep our patient – clinician relationship separate from my role as a Trustee and then Chair of the Society. I certainly do not remember ever being put under any pressure by him. Any discussion we did have was warm and conversational.

226. In any event, no such conversation would have had any bearing on the decisions taken by the Society. We were committed to our campaign aims and these were decided through the Board.

227. Professor Hay's comment on the corrosive effect of the campaign on doctor – patient relations is interesting. It is undoubtedly true that the infected blood disaster will have caused a degree of corrosion of this nature. It is the infected blood disaster that caused any corrosion though, not the campaign for an Inquiry into it. If an Inquiry had been held in good time and with the support of the clinician community, then the corrosion could have been limited and stemmed.

Q80. In your evidence to the Archer Inquiry [ARCH0000010, page 40], you said that you hoped that the Archer Inquiry would recommend that the British Government would adopt a model similar to the Irish settlement. Please provide details on what other efforts the Society engaged in to achieve a similar model.

228. The Society's second Submission to the Archer Inquiry included our best proposals at the time for a compensation model.

229. That effectively supplanted any prior proposals.

7.5 Other Campaigns

Q81. For any other campaigns relevant to the Inquiry's Terms of Reference which were organised by the Haemophilia Society, please explain, giving as much detail as you are able:

a. When and why the society launched these campaigns, including any particular events which prompted it;
b. Their aims;
c. Whether those aims changed and, if so, why;

d. Any obstacles the Haemophilia Society faced in achieving those aims, including, but not limited to, internal disagreements within the Haemophilia Society;
e. Whether the Haemophilia Society achieved its aims;
f. If so, when the Haemophilia Society achieved its aims;
g. If not, what the result of these campaigns were.

230. I believe that the campaign activity of the Society has been covered in the prior questions. I cannot remember any other key campaign activity.

Section 8: Interaction with Trusts and Schemes

8.1 Structure and Organisation

Q82. 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.

231. I don't have a record of this I'm afraid. Any Society Trustees or committee members involved in such a way would have been noted in Society records.

Q83. Please detail your involvement with the trusts and schemes in your role at the Haemophilia Society.

232. I had limited involvement with the trusts and schemes in my role at the Society. It wasn't a core area of knowledge for me and my time was constrained. From memory, most interactions would have been with the Society's Chief Executive.

233. I would have written to the Chair or Chief Executive of trusts and schemes when matters of interest or concern arose as directed by the Trustee Board.

234. My answers to the following questions are all quite brief as a result and I hope that the Chief Executives of the Society will be able to answer more fully.

235. My knowledge is best summarised in the Related Organisations section of the Society's first Submission to the Archer Inquiry (pages 4 and 5).

236. If there are outstanding issues, then I would be very happy to review all relevant papers (Society Trustee Board papers) and communications and produce a fuller statement.

8.2 Relationship with The Macfarlane Trust

Q84. Please detail your involvement with the Macfarlane Trust, and the relationship between the Haemophilia Society and the Macfarlane Trust.

237. I had limited direct involvement with the Macfarlane Trust but worked with the Trust's Chief Executive and Chair as required. The closer working relationship was typically with the Society's Chief Executive.

238. The relationship between the Macfarlane Trust and the Haemophilia Society is as described in the Society's first submission to the Archer Inquiry (page 4).

239. Certainly, at that time, the Macfarlane Trust had 12 trustees, four of whom were appointed by the Society.

Q85. What role did the Haemophilia Society play in the operations of the Macfarlane Trust? What role did the Society play in making grants, or in making decisions about grants, on behalf of the Macfarlane Trust?

240. I don't believe that the Society played a direct role at all in Trust operations. In answering subsequent questions however, I see that in HSOC0019926_005 that I did write in 2007 to challenge some grant policies (not cases) and offering to help with a review of the policies.

Q86. Did you encounter any problems with the Macfarlane Trust whilst performing your role in the Haemophilia Society and If so, how were they resolved?

241. I don't remember problems. Any that were encountered would be detailed in Trustee Board papers.

Q87. 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.

242. I don't believe that I attended any Macfarlane Trustee meetings.

Q88. How often did the Haemophilia Society and the Macfarlane trust meet? Please detail how often the two organisations communicated.

243. I did not have regular meetings with the Trust. I believe the Chief Executives met on a regular basis (monthly perhaps).

Q89. Please detail the relationship and the nature of the discussions that you had with the Chair, the Chief Executive and any other members of the Macfarlane Trust.

244. I don't recollect having a particularly close working relationship with the Chair, Chief Executive or other members of the Trust. I had a cordial introductory meeting when I became Chair I remember and after that we engaged when there was reason to.

Q90. Did the Haemophilia Society have any influence on or involvement in selecting a new Chairman for the Macfarlane Trust?

245. I don't believe the Society has influence or involvement in this.

Q91. 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?

246. The Society appointed 4 Trustees of the Trust and the Chief Executive of the Society met regularly. I do not consider that I, personally, had any influence over any aspect of the Trust.

Q92. 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.

247. I don't remember the details of the appointment process. The composition of the Board was per my answer to Question 84. I did not remember the composition changing when first drafting this response but noted that it did from reviewing the Trustee Board Minutes provided to me in March. I note that it was questioned (see question 94 below).

Q93. Did the Macfarlane Trust reject any of the nominations for Trustee from the Haemophilia Society?

248. I don't remember any nominations being rejected. All nominations and any subsequent issues would have been within Society Trustee Board papers.

Q94. Please explain the situation regarding the appointment of the Haemophilia Society nominated Trustees on the Macfarlane Trust which Peter Stevens wrote to you about on 30 April 2004 [HSOC0020088]. How did the Society respond to the Long Term Review's recommendation that the Society's power of appointment be reduced to a single Trustee. How did the Society respond to Peter Stevens' suggestion that the Society should have the right to appoint a "maximum of two individual Trustees to the Trust". Was this matter resolved and, if so, how?

249. I have reviewed the additional Trustee Board Papers provided in March 2021 and have been able to track this though.
250. There were a number of updates on this matter in 2004 and 2005 and Peter Stevens and Martin Harvey attended as guests at Haemophilia Society Trustee Boards to discuss this matter.
251. The clear outcome was a reduction from 6 Haemophilia Society appointed trustees to 4, but not the 1 that had been proposed. This was concluded at the Trustee Board on 4th May 2005.

Q95. Please explain the situation regarding the appointment of the Haemophilia Society nominated trustees on the Macfarlane Trust which you wrote to Martin Harvey about on 22 May 2007 [MACF0000080_002]. Was it a common occurrence that the Macfarlane Trust did not comply with the terms of the appointment of these seats? Was this matter resolved and, if so, how?

252. I am afraid that I don't know if this was a common occurrence or how this particular matter was resolved.

Q96. Was it a common occurrence that Macfarlane Trust sat in on trustee interviews? Did they have any influence over the choice of candidate? Were there challenges from the Macfarlane Trust in the appointment process? If so, on what grounds were challenges made and how frequently did this occur? [You may wish to refer to MACF0000016_004 to assist you.]

253. I do not know the answer to this question I'm afraid.

Q97. Please detail the level of overlap of personnel and, if any, the overlap of responsibilities between the Macfarlane Trust and the Haemophilia Society. Do you believe that any overlap impacted the way in which either group was run and the decisions that were made? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

254. I am not aware of overlap of personnel. Any conflicts of interest would have been recorded. I can only answer for the Society, but I don't recollect any impact that the Trust had on how the Society was run or the decisions that were taken by our Trustee Board.

Q98. Please explain the reasons why it was thought that any conflict of interest would be *"unlikely"* by appointing Roger Evans as interim Chief Executive of the Haemophilia Society while he was a trustee of the Macfarlane Trust. Please detail what the Society's procedure regarding conflicts of interest consisted of. Had there been previous conflicts of interest? If so, please provide details. [You may wish to refer to HSOC0027877 to assist you.]

255. I can only answer with hindsight and my opinion is that any conflict would have been unlikely given the different operational scope of the Society and the Trust.

256. The Trustee Board papers would have confirmed Roger's appointment and any potential conflict of interest. His position as a Trustee of the Macfarlane Trust would have been noted.

257. I cannot recall the Society's conflict of interest process, but I do know that there was a documented process – it should be available from the Society.

Q99. 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?

258. I have no knowledge of the levels of communication between different trustees of the Macfarlane Trust.

Q100. To the extent that you have not already answered this above, please provide details of your involvement in determining applications for financial assistance and support at the Macfarlane Trust.

259. I do not believe that I had any involvement in these matters.

Q101. Did you encounter any problems between the Haemophilia Society and the Macfarlane Trust during your tenure? If so, what were they and how were they resolved?

260. It is clear from reading the Trustee Board minutes that there was some tension between Society members and Trustees and the Macfarlane Trust. My recollection is of getting sufficiently involved to resolve distinct issues (e.g. the number of Haemophilia Society appointed Trustees) but no more so due to competing demands on time.

8.3 Government Support of trusts and schemes

Q102. What involvement, to the best of your knowledge, did the Department of Health or any Government department have in the following:

a. the organisation of any of the trusts and schemes;
b. the funding of any of the trusts and schemes; and
c. the running of any of the trust and schemes, including aims and objectives and functioning.

261. I don't have the knowledge to answer this question.

Q103. Did you consider that the funding provided to the Macfarlane Trust by the Government was adequate? Please explain your answer.

262. I do not believe the funding was adequate. The Society's first submission to the Archer Inquiry (p4) stated this and expressed disappointment that the Trust's business case for increased funding was turned down.

Q104. 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 response was received from the Department of Health.

263. The Society raised concerns about funding of the Trust, but I do not have the details of this. It would be clear from Trustee Board packs.

Q105. 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?

264. I do not have an opinion on this.

8.4 Relationship with other trusts and schemes

Q106. Please detail the relationship, and the level of contact, 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
d. The MFET

265. The Skipton Fund and the Eileen Trust are described in the Related Organisations section of the first submission to the Archer Inquiry (pages 4 and 5). The Society will hold details of the actual relationships.

Q107. Please comment on any difficulties or shortcomings you encountered with the above mentioned trusts and schemes during your time at the Haemophilia Society.

266. I do not remember any difficulties or shortcomings. Any issues would have been raised and tracked through the Trustee Board.

Q108. In your evidence to the Archer Inquiry on 30 August 2007 you said that "there should be no more trusts or funds and that is no way a criticism of the individual trusts and funds; they were set up as they were set up, but that is not what we want going forward" [ARCH0000010, page 38]. Please could explain what you meant by this comment. Did you consider that they were difficulties in how they had been set up? What caused you to recommend the abandonment of the trusts and schemes structure of compensation?

267. The full rationale behind this statement is in the Society's second submission to the Archer Inquiry. In essence my belief is that there should be one scheme providing direct financial relief. The Archer Inquiry recommended this in their report - Recommendation 6, pages 108 to 110.

Q109. Please comment on the efficacy of those Alliance House Organizations ("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.

b. What if anything do you consider the Macfarlane Trust, or any of the other AHOSs, should have done differently?

c. Do you consider the Macfarlane Trust, and the other AHOSs to have been sufficient for the goal they were set up to achieve?

268. I am not really qualified to comment on the efficacy of these organisations. The opinions of those who use their services would be key here.

269. My opinions go back to 2007 but these organisations were clearly not set up in a manner or with the requisite funding to meet the needs of those they were set up to serve.

Q110. What were the issues with the Skipton Fund appeals process referred to in [HSOC0019926_003, page 2]? What was the impact of the issue? Was this issue ever resolved? If so, please explain how it was resolved.

270. I cannot remember these issues or whether they were resolved. I would hope that the Society holds the correspondence.

Q111. In light of the structure and administration of the Skipton Fund, did you consider it to be sufficiently independent? Please provide as much detail as possible.

271. I do not have an opinion on this as I was not sufficiently close to the workings of Skipton.

Q112. In [CAXT0000077_123] Peter Stevens refers to the new Chairman of the Macfarlane Trust as having "no family interest in the Trust". Was this a requirement sought for the new Chairman of the Macfarlane Trust? Why was this considered to be of a benefit? Had the previous "family interest" been an issue for Reverend Tanner and Peter Stevens? If so, please provide as much detail as possible.

272. I am not aware that this would have been a requirement and I am not aware of a 'family interest' having been an issue. Most people who chose to become involved in a voluntary capacity with the Society or the Trust will have a personal connection (either directly or through a family member). Such connections or interest would be noted, certainly at the Society and I am sure at the Trust.

Q113. Do you consider that any overlap in personnel between the different AHOs impacted the way in which they were run and their independence from one another? For instance, Peter Stevens being the Chairman of the Macfarlane Trust, Director at the Skipton Fund and Chairman of the Eileen Trust. Please detail any other similar overlaps between the AHOs.

273. I do not have an opinion on this.

Q114. To what extent (if any) was the opinion of the AHOs informed by the views of the Society's membership? Did these differ from the views of the Haemophilia Society's Executive Committee, as you understood them?

274. This would have been reflected by the views of Society appointed trustees. Other than that statement of fact I do not have an opinion on this.

Q115. 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.

275. This will be detailed in Society records, but I do not remember this I am afraid.

Q116. How often was the Haemophilia Society asked to get involved in applications made to the AHOs by individuals? How often did the Haemophilia Society get involved with applications made to the Macfarlane Trust? If so, please provide details on which forms the involvement would take and what level of involvement the Society would have, and whether the Macfarlane Trust were receptive to any involvement.

276. I do not have any knowledge of this. I do not believe that the Society would have got involved.

Q117. Further to the above questions, if the Haemophilia Society did get involved with individual applications, did the likelihood of success or acceptance of the application increase?

277. I do not have an opinion on this.

8.5 Tanner Fund

Q118. The Haemophilia Society ran the 'Tanner Fund' as referred to in [HSOC0023074, page 9]. Please provide as much detail as possible on this fund. Why was this fund created? When, and by whom, was it set up? What were the objectives and goals of the fund? Were these goals achieved? If you have any documents relating to the Tanner Fund, please provide them.

278. I don't have details of this fund I'm afraid or any documents about it. I do remember that it's use was reviewed at Trustee Board meetings and it is referenced in Board papers and minutes.

Q119. Please explain what the guidelines of the Tanner Fund were, as referred to in [HSOC0019926_003].

279. I don't recall these I'm afraid. The paper states that the guidelines were attached, and I presume that the Society will have a copy of all papers provided to Trustee Board meetings.

Q120. Please explain what constituted an emergency application, as referred to in [HSOC0019926_003], and the process for handling them.

280. I do not remember this I'm afraid.

Q121. Please explain the fund allocation process in detail. What was the criteria that had to be satisfied to receive funds? Who monitored the fund? Where did the money contained in the fund come from?

281. I do not remember this information I'm afraid.

Q122. Please explain what the concerns were regarding the allocations process referred to in [HSOC0019926_005, page 5]. How were such concerns resolved? How were decisions about allocations made?

282. Again, I do not recall the concerns other than issues about timeliness of replies to applications, I think. I would hope that the Resources Sub Committee minutes would have more detail and that the actions agreed would have updates provided.

Q123. What was your role on the Tanner Fund Panel, as referred to in [HSOC0019926_004, page 4]?

283. I did not recall being on the panel, but this reference means that I did serve as part of the panel and I would been part of reviewing applications.

Q124. Please identify the members of the committee for the Tanner Fund. Please detail the selection process for this committee, including any required skills or experience. What format did the meetings of the committee take? Were minutes of these meetings recorded?

284. I do not hold these details. Meetings and decisions would have been recorded as a matter of course.

<u>Section 8: Relationship with Pharmaceutical Companies</u>

9.1 Financial Relationships

Q125. Please list all pharmaceutical companies that provided direct or indirect financial support to the Society.

285. I do not have a list of these available to me. Records were kept by the Society, however, and should be available.

Q126. To what extent did the 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 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.

286. I do not have the details of this available to me. Funding was received from companies that manufactured and / or supplied treatment products including clotting factor.

287. The level of funding was noted in the Annual Report and Financial Statement each year. I have provided a summary of funding sources during my tenure at question 131 below. The level of corporate funding appears broadly stable throughout, albeit with an increase in the final year.

288. There was regular discussion of such funding at Resources Sub Committee and at the Trustee Board. There was a policy to govern such funding which has been shared with me now.

Q127. Was the Society's relationship with BPL different to its relationship with the pharmaceutical companies? If so, please explain how. [HSOC0029689_041 may be of assistance].

289. I am not aware of how this relationship would have been differentiated. I note from HSOC0029689_041 that BPL were invited to attend a Board Meeting to discuss the safety of Plasma products.

Q128. What monies, if any, were provided to BPL over your tenure? What benefit did the Society derive from the relationship with BPL? Were research funds provided to any of the pharmaceutical companies?

290. I am not aware of any funds being provided to BPL. I would have to review all Research grants to check whether any were provided to pharmaceutical companies but would find that unlikely.

Q129. 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.

291. My memory is that the relationship would be between the Chief Executive of the Society and the relevant executive of the pharmaceutical company. Any proposals for funded activity would be reviewed and approved / rejected / requested to be amended by the Trustee Board.

Q130. How, if at all, did the Society's fundraising activities develop over your tenure? What factors or activities, if any, contributed to increasing or decreasing financial contributions to the Haemophilia Society from pharmaceutical companies manufacturing and/or supplying blood products?

292. It is clear from Annual Reports and Trustee Board papers that fundraising was an issue at the start of my tenure and remained so at the end. We often attempted to broaden the funding base and relied on a mixture of:
- Government grants (although often with the prospect of these reducing / being withdrawn)
- Corporate funding
- Fundraising activities by members and local groups
- Grant applications
- Legacies.

293. I am not aware of any significant factors that contributed to changes in the contributions from pharmaceutical companies.

Q131. What proportion of the budget of the Society was raised through fundraising during your tenure?

294. The sources of funding was broadly stable over my time with the Society although the level of Government grants fell.

295. A short summary is as follows:

	12/2001	12/2002	12/2003	12/2004	12/2005	12/2006	3/2008 15 months
Subscriptions	16,896	20,172	22,448	29,563	26,566	24,601	20,877
Government Grants	158,000	125,000	115,000	110,000	110,000	107,500	97,500
Corporate	151,023	153,052	147,177	134,566	121,132	123,267	217,636
Other grants / donations	366,139 *	214,775	238,237	211,140	171,358	146,532	189,429
Legacies	42,500	2,857	49,715	14,920	128,492	199,147	151,471
Gifts in Kind	-	-	-	-	-	29,000	15,000
Local Group activities	38,145	52,355	73,462	50,047	39,615	23,510	29,945
Annual Draw and events	49,903	58,857	64,114	54,979	95,811	64,263	86,198
Investment Income	28,683	20,987	22,130	22,855	25,977	17,463	24,128
Other Income	6,285	44,756	30,949	13,416	12,337	4,463	4,4244
Total	857,574	692,811	763,232	641,486	731,289	739,746	836,428

*GMTV appeal of £136,833

Q132. Were Society members aware of where the money they raised or donated was being spent?

296. Most funds raised were not restricted in terms of use – that is to say that they would be spent on the various activities of the Society.

297. If funds were asked to be used for a specific purpose, then they would be classified as designated (restricted) funds for that purpose and noted as such in the accounts.

Q133. Was the 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? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

298. From memory, funding from the pharmaceutical companies was typically for general purposes. Sometimes funding in kind was given (e.g. to host or provide facilities at events) and such funding was noted in the accounts.

299. If a pharmaceutical company had a particular activity that it wanted to fund, then the proposal would be considered by the Trustee board for approval.

300. If the Society had particular activities that it wanted to fund, then the Chief Executive could reach out to see if a pharmaceutical company would be interested in supporting it. Such activity would be noted at Trustee Board.

301. It is always interesting to query what the pharmaceutical companies' expectations were of their funding. I am not aware of any direct expectations but clearly there were benefits of publicity and good will from involvement in events and sponsorship of activity.

Q134. 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?

302. The Chief Executives would be better able to answer this question than I. We did of course track which companies provided funding and at what level both in absolute and relative terms. There will be a breakdown of this held by the Society, but I don't remember specific companies that stood out.

Q135. What, in your view, were the motivations or expectations, if any, of pharmaceutical companies who donated to the Society? Was there an expectation that the Haemophilia Society would provide anything in return and if so, what?

303. Please see answer to question 133.

Q136. A number of the Haemophilia Society Bulletins thanked a range of pharmaceutical companies for providing "valuable support" including Aventis Behring, Baxter, Bayer, BPL, Novo Nordisk, Roche, Schering, Plough, Wyeth/Genetics Institute [e.g. HSOC0023040, page 2]. Was that record a requirement of their funding? What was agreed in this regard? If so, how was this agreed?

Q137. 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, Nordic Pharma, ZLB Behring, Novo Nordisk, BPL, Grifols, Roche, Schering Plough and Wyeth Pharmaceuticals [e.g. HSOC0023074, page 16]. Was that record a requirement of their funding? What was agreed in this regard? If so, how was this agreed?

304. I do not believe that this was a requirement of their funding. I think, rather, it ensured that there was visibility that funding had been provided and by who.

Q138. To what extent, did the Society, through its activities and functions, attempt (if at all) to assist pharmaceutical companies to promote their products and/or public image? If so, please provide details, specifying the pharmaceutical companies, the products, the Haemophilia Society's activities and functions, and the way in which these activities and functions promoted the pharmaceutical companies products and/or public image.

305. I don't believe that there was such promotion. It would have been visible that a company was providing support at a sponsored event but there was no link to promotion. Doubtless, the public image of a company could be seen to be improved by visibly sponsoring or funding activities, but this was not an endorsement or promotion.

Q139. To what extent did pharmaceutical companies rely (if at all) on the Haemophilia Society to improve their public image through its activities and functions? If so, please provide details, specifying the pharmaceutical companies as well as the way in which the Haemophilia Society were expected to improve their public image.

306. I do not believe that there were such reliances or expectations.

Q140. Did the Society publish or disseminate any articles or publications in exchange or with the expectation of receiving financial contributions, or any other benefit, by pharmaceutical companies? If so, please provide details on the nature of these articles or publications.

Q141. Did the Society refrain from publishing or disseminating any articles or publications in exchange or with the expectation of receiving financial contributions, or any other benefits, from pharmaceutical companies? If so, please provide details on the nature of these articles or publications.

307. I do not believe that the Society either published / disseminated or refrained from publishing / disseminating any articles or publications in this way.

Q142. In the Autumn 2007 edition of HQ [HSOC0023072, page 10], there was an article advertising 'NovoSeven'. Did Novo Nordisk pay for this article? Was this part of a commercial arrangement with the firm? Was this product independently researched and approved before the article was included? Were all product advertisements approved by a clinician prior to publication?

308. I don't know the answers to these questions I'm afraid. I suggest that they are followed up with the Society and perhaps Chris James will have an answer.

309. I've re-read the article several times and although I would like to believe it was intended as an update in terms of Factor VII treatment it does read like an advert / promotional piece and I'm not comfortable with it at all.

Q143. In your evidence to the Archer Inquiry on 30 August 2007 you said that obtaining funding from pharmaceutical companies "is a cause of potential unease and difficulty" [ARCH0000010, page 44]. Please expand on this comment and, in light of it, please detail the nature of the relationships the Society had with pharmaceutical companies. Please detail how you navigated these relationships.

310. The comment is really just a statement of fact. Any patient group charity that accepts funding from commercial pharmaceutical companies that profit from their treatment needs to have effective policies in place to govern that funding.

311. A patient group that has suffered from infected treatments will feel even more strongly about that, hence the need for care and the potential unease and difficulty.

312. As per previous answers the relationships between the Society and pharmaceutical companies would typically have been handled by the Chief Executive.

Q144. You added that it was the Haemophilia Society's policy to "not accept funding for one pharmaceutical for a particular thing" [ARCH0000010, page 44]. Please could expand on this comment and provide as much detail as possible on this policy. In light of this comment, please could you explain how sponsored events such as the World Haemophilia Day sponsored by Bayer [HSOC0019926_002, page 5] and the article advertising 'NovoSeven' [HSOC0023072, page 10] fit into this policy.

313. I have reviewed this now against HSOC0003587 (Haemophilia Society Policy of Working with Commercial Organisations). It states as a principle that 'In order to safeguard our independent standing, wherever possible, we prefer to have multi-sponsors for our work. This is particularly the case in relation to publications, such as our booklets and Bulletin, where sponsorship from one company alone might give the impression of bias. Hence, in general we will seek more than one sponsor for each of our publications and for events with people with haemophilia.'
314. My statement to Archer above reflects this policy and principle. That is to say we would prefer not to 'accept funding for one pharmaceutical for a particular thing'.

315. From time to time we would have agreed to single company sponsored events such as the Bayer World Haemophilia Day event mentioned in the question, especially if we couldn't find co-funding.

316. I don't believe that the Novo 7 article was in line with the Society's policy, however. The policy states that 'As a general principle we will not endorse any brand of treatment product….' This article should have been made generic and not included the product name.

9.2 Other Relationships

Q145. Did the Society rely on pharmaceutical companies for assistance or support, other than financial contributions? If so, please provide as much detail as possible on the support provided, the specific activities/functions that pharmaceutical companies supported, and the names of pharmaceutical companies involved.

317. Non-financial contributions were sometimes provided, particularly in terms of donated facilities for conferences and events.

318. These were latterly stated in the Annual Report and Financial Statements as gifts in kind. (from year ended 31 December 2006).

Q146. What relationship did the Executive Committee members of the Haemophilia Society have with pharmaceutical companies? Did any representatives of pharmaceutical companies join the Haemophilia Society, either while they still worked for the pharmaceutical company or after they left?

319. I am not aware of any relationships that Trustees of the Society had with pharmaceutical companies and any such relationships would have had to have been declared as conflicts of interest.

320. Representatives of pharmaceutical companies may well have joined the Society as a member, but I am not aware of anyone having held a position of responsibility. Again, any current or past involvement with a pharmaceutical would have been material and therefore declarable.

Q147. To what extent did the Haemophilia Society rely (if at all) on communications from pharmaceutical companies for assurances or opinions on the safety of blood products? If so, please provide as much detail as possible on the points of contact in pharmaceutical companies, the advice provided, the issues raised, and the frequency of these communications.

321. I do not have the knowledge to answer this question but do not believe that the Society would have relied on such statements.

Q148. Which pharmaceutical companies did the Haemophilia Society have a relationship with during your tenure? Who were the main points of contact?

322. I do not have a record of this but would suggest that the Society itself would hold such a record.

323. The Haemophilia Alliance also held Industry Forums and again, there will be records of these events also.

Section 10: Other Issues

Q149. 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?

324. To the best of my knowledge, no at any point and no during my tenure.

Q150. 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.

325. I do not have anything further matters to add.

Statement of Truth

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

Signed Roderick Morrison

Dated 3rd May, 2021