Witness Name: Christopher Lloyd James
Statement No: WITN5683001
Exhibits: WITN5683002
Dated: 26/08/2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHRISTOPHER LLOYD JAMES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 May 2021.

I, Christopher Lloyd James, will say as follows: -

Section 1: Introduction

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

1. As set out above, my name is Christopher Lloyd James of GRO-C GRO-C. I was born on GRO-C 1961. My professional qualifications are set out in the curriculum vitae annexed [**WITN5683002**].

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.

2. My employment history is set out in the curriculum vitae annexed [**WITN5683002**].

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.

3. I represented the Haemophilia Society on a number of external bodies. I'm afraid I can't recall them all. However, I represented the Society at World Federation of Haemophilia (WFH) and European Haemophilia Consortium (EHC) meetings. I attended a number of MacFarlane Trust beneficiary meetings during my tenure

4. I was also a member of the Pan-London Primary Care Trust ('PCT') Consortium Commissioning Group as a patient representative. I cannot recall the dates I acted in that role. The role of this group was discussing high-cost bleeding disorder patients, agreeing the appropriate treatment approach and seeking agreement of commissioners for that treatment.

5. I also sat on the Specialised Health Care Alliance (possibly for the whole of my tenure). The role of the Alliance was to represent the needs of patients who fell under the criteria of specialised services to Government. There were a number of voluntary organisations and industry representatives.

6. As CEO I also attended meetings of the UKHCDO. These included the annual meetings to talk about the work of the Society and more regular meetings to discuss data analysis.

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 or letters to the Archer Inquiry [ARCH0000010, pages 46 and 51; ARCH0001927; ARCH0001014; ARCH0003264; ARCH0001232; HSOC0013800] that you do not consider to be true and accurate, please explain what they are.

7. I have reviewed documents ARCH0000010; ARCH0001927; ARCH0001014; ARCH0003264; ARCH0001232; HSOC0013800 and although a significant amount of time has passed, to the best of my knowledge and recollection, I believe the matters contained within my oral evidence and letters to the Archer Inquiry to be true and accurate.

8. To the best of my knowledge and recollection, I do not considered there to be any matter within the oral evidence or letters that are not true and accurate.

Q5. Please consider the letters which you sent to the Penrose Inquiry. Please confirm whether the content is true and accurate. If there are any matters contained within your letters to the Penrose Inquiry [PRSE0000851] that you do not consider to be true and accurate, please explain what they are.

9. I have reviewed the letter [PRSE0000851] and although a significant amount of time has passed since it was written, to the best of my knowledge and recollection, I believe the content of the letter is true and accurate. To the best of my knowledge

and recollection, I do not consider there to be any matters contained within the letters to the Penrose Inquiry that are not true and accurate.

Q6. Please confirm whether you have provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. If you have, please provide details of your involvement and copies of any statements that you made.

10. To the best of my knowledge and recollection, I have not provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to HIV, HBV and/or HCV infection and/or variant vCJD in blood and/or blood products.

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

Q7. The Inquiry is aware that you served as the Chief Executive of the Haemophilia Society, from 2006 to 2013 [HSOC0023068]. Please confirm and explain what your role and responsibilities were in relation to this position and how your role and responsibilities changed over time. If you held any other positions within the Haemophilia Society, please set them out.

11. I was Chief Executive Officer ('CEO') of the Society from June 2006 to 2013. I held no other positions. My responsibilities did not significantly change in that time.

12. As CEO, I was responsible for the day-to-day running of the Society. This included working with the Board of Trustees, all operational and strategic work. I supported the Chair and Board in all matters, including acting as Company Secretary and managing governance. Although my responsibilities did not change after the restructure of the Society's staff team I was more involved in areas such as fundraising and finance. My CV gives some further detail about my role and responsibilities [**WITN5683002**]

13. As the Society is a small charity, there was no senior management team as such and I had responsibility for all aspects the work including income generation, staff management, budgeting and human resources.

Q8. Please confirm and outline your role and the responsibilities within the Society, including responsibilities held in relation to other groups and organisations. If these changed over time, please detail when and why.

14. The main aspects of my role within the Society are outlined above. In relation to other external bodies, including alliances, related organisations and groups I was most often the lead contact, although in a number of cases colleagues were involved in this work. My role was to represent the views of people with bleeding disorders and the Society's aims to the best of my ability. I was not a Board member of any other organisations.

15. In terms of changes over time, in 2007/8 it became clear that the Society had some significant financial problems due to large parts of its income being tied up in restricted funds – these are funds which are given for a specific purpose and cannot be spent on other costs. These grants are vital for an organisation of this size. However, there is always greater pressure on unrestricted funds, which are often harder to raise. The Society had an imbalance between its restricted and unrestricted funds (funds needed to run the organisation). That necessitated a significant restructuring, with loss of staff. The restructure impacted on my role including through an increased responsibility for income generation. That involved increasing income from major donors and looking for new community fundraising opportunities. It is my view that the Society came very close to having to cease operations at this time. Although the situation did improve, the Society was always looking very closely at its cash flow to the extent that for a while we were looking at daily cash flow reports.

Q9. When you joined the Haemophilia Society, and throughout your tenure, what were the objectives and functions of the Society? If these changed over time, please detail when and why.

16. It is my recollection that the functions and objectives of the Society remained much the same throughout my tenure. The objectives broke down into three main areas:

(a) The campaign for a Government contaminated blood inquiry;
(b) Support for people affected by bleeding disorders; and
(c) Influencing the services provided for people affected by bleeding disorders.

17. The functions of the Society included providing a support service for people with bleeding disorders and their families, running activities for children with bleeding disorders, provision of written information in publications and on the website, a benefits support service, campaigning on the issues of contaminated blood and

influencing the services provided by statutory services for people with bleeding disorders.

Q10. Please describe how the organisation was structured, including the governance arrangements and the day to day management and running of the Society. Please set out the line management arrangements of staff including who your line manager was and the nature and extent of their management of you and oversight of your work. If this changed over the period of your tenure, please set out those changes.

18. The Society was governed by the Board of Trustees with a small number of sub-committees; I can't recall how many or what they were.

19. I was managed by the Board, through the Chair. I was managed directly by the Chair – this involved regular meetings and phone calls to cover all aspects of my work. With a change of Chair in or around 2011, I feel this oversight increased with more regular meetings with the new Chair and more regular reporting. I managed a small number of staff across all functions. There was a small hierarchical reporting structure – approximately three direct reports to me and approximately twelve staff in total prior to the restructure, but the organisation was much flatter post restructure and it is my recollection that I 'line managed' all staff after this – approximately six staff.

3.1 Sub-committees, task groups and advisory bodies

Q11. Please list all the different Society sub-committees, task groups and advisory bodies that you were involved in and describe the purpose, functions and responsibilities of each committee, task group and advisory body.

20. I sat on a number of sub-committees of the Board and, on prompting, I recall a resources and finance sub-committee, information and communications sub-committee and a medical advisory panel. I can't recall the exact functions of these groups.

Section 4: Communication and Dissemination of Information by the Society

4.1 Publications

Q12. Please identify the members of the Executive Committee and/or committees of the Haemophilia Society responsible for editing and selecting material for

the Haemophilia Quarterly ("HQ") and other Haemophilia Society publications during your tenure.

21. I don't recall any specific involvement from the Executive Committee ('EC') in the production of publications such as HQ, although I'm sure trustees, in particular the Chair would have been involved in the development of some articles in my time as CEO. I would have discussed these articles with Chair and/or trustee involved.

Q13. To what extent, if any, did representatives of pharmaceutical companies assist in proposing and/or editing and/or selecting material for the Haemophilia Society's publications?

22. Editorial responsibility for the Society's publications was with the Society. I'm sure there were articles which necessitated some input from industry, perhaps in terms of their activity. My recollection would be that this was restricted to data/statistical information. To the best of my knowledge pharmaceutical companies did not assist in proposing, editing or selecting material for the Society's publications.

Q14. How did the Haemophilia Society select or identify contributors and interview subjects for its publications? What were the criteria, if any, for someone to be able to write an article for a publication?

23. I'm sorry I don't recall in detail how the Society selected or identified contributors and interviewed subjects for its publication. To the best of my recollection and knowledge there would have been a balance of news items: both where contributors selected themselves, as they were the story and where we sought out contributors for issues we wanted to commission items on for example, changes to the benefits system.

Q15. Specifically, in relation to its publications which gave medical and/or other similar opinions including those on treatment options:

a. How were the contributors identified?

24. I'm sorry I can't recall how the contributors were identified, apart from the general breakdown mentioned above in response to question 14.

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

25. There were no health professionals employed by the Society so there would have been times that we'd need expert input. I don't recall this being very often.

c. ***If medical professionals were relied upon, please provide the names of the medical professionals.***

26. I'm sorry I can't recall the names of the specific health professionals that would have been asked but I would certainly have spoken to Debra Pollard (Royal Free Hospital) and Kate Khair (Great Ormond Street) who were specialist haemophilia nurses who in my tenure sat on the Board.

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

27. I can't recall a process for deciding which medical professionals should be approached for any such advice, (or who it was decided by). It would have depended on the subject matter of the article and the necessary expertise to comment.

e. ***Whose responsibility was it, within the Haemophilia Society, to seek any such advice?***

28. I'm sorry I can't recall whose responsibility it was, within the Society, to seek any such advice. I think it is likely that there were occasions when I did this, and I'm sure that members of the support team may also have done this. However, I cannot recall any specific examples of doing so.

f. ***Please set out all examples, relevant to the Inquiry's Terms of Reference, of when the Society provided medical advice and/or opinions in its publications.***

29. I don't think the Society would have provided direct medical advice to people affected by bleeding disorders in my time as its role was to provide to support. We did give some advice on access to benefits.

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

30. See my response to questions 15(b – e) above.

Q16. In your evidence to the Penrose Inquiry you stated that, "the activities of the Society in disseminating information to its members were often spearheaded by haemophilia doctors" [PRSE0000851, page 3]. Please expand on this statement:

a. What dissemination of information, if any, that is relevant to the Inquiry's Terms of Reference was spearheaded by the Society during your time in office?

31. I think that the statement *"the activities of the Society in disseminating information to its members were often spearheaded by haemophilia doctors",* would have been a reference to the Society being dependent, at that time, on current medical advice and the information that the Society could provide at that time was through health professionals. I don't recall the Society 'spearheading' information in my tenure.

b. Which doctors particularly spearheaded these activities?

32. I'm afraid I can't recall the names of particular doctors who would have been involved.

4.2 Communication to members

Q17. Please state which methods of communications you used to interact with members during this time? What were the main concerns and issues reported or relayed to the Haemophilia Society? How did you respond to the concerns?

By 'during this time' I have presumed you are referring to my tenure as CEO. The method of communications used by the Society to interact with members would have depended on the type of information being disseminated. The main tool was the magazine (HQ) but there were occasions when we used direct mailing or email messaging. These would have been used for more urgent and important information. We also sometimes gave updates at meetings such as AGMs.

33. As I recall the main areas of concern that were reported to the Society were financial worries due to lack of income and access to benefits for which we had a benefits support service. The campaign on contaminated blood was a major issue and there was regular contact with campaigners. My colleague, Dan Farthing and I would usually respond to these personally with regular phone calls and emails.

Q18. Did the Haemophilia Society receive enquiries from the public or members who required advice on blood product treatment? If so, how were these queries handled? Who would respond? Please set out specifically, to the best of your knowledge, what advice and/or information the Society had in order to respond to these queries and from whom that had been provided.

34. The only specific query that I can recall was concern from one or two patients who felt that they weren't getting on with their blood product and wanting to change. I recall that we advised them that they should be able to do this after discussion with their health professional team. After the Department of Health tender for blood products – I'm unsure of the year – there was some concern from some patients that their product had changed. We reassured that they should be able to go back to their original product.

Section 5: Relationship with the Government

Q19. Please describe the extent of your role and involvement with regard to the Society's interactions with and representations to the Government. [You may be assisted by HSOC0011184_003].

35. My role was to lead the Society's interactions with Government. Lord Morris of Manchester, the Society's President, played a significant role in the interaction with Government and I liaised with him almost on a daily basis. This role included lobbying and campaigning. Over the seven years I was CEO this work including contact with Government (letters and meetings), working with supportive MPs, the organisation of campaign demonstrations and meetings with decision-makers in Parliament. These demonstrations and meetings included members of the affected community.

Q20. Please set out the Haemophilia Society's interactions with the Government, addressing:

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

36. I can't recall exactly when or how often the meetings took place but in seven years we met with Ministers and officials on a number of occasions.

b. Who did you meet with?

37. I remember meeting a number of health officials including Anna Soubry and her predecessor Anne Milton.

c. How did the Haemophilia Society choose who would attend key meetings with Government officials and civil servants?

38. The Society always tried to have representation from campaign groups and individuals affected at key meetings with Government officials and civil servants. It was sometimes challenging to make the representation manageable in terms of size (as we could only have a limited number of people attend) but we tried to ensure as many groups and individuals were included.

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

39. On occasion there were minutes of the meetings recorded, I think. Mostly though, we tried to ensure someone from the Society took a note sent to the Ministers to check it with them. I do remember there were occasions they didn't reply and we then took that they were comfortable with the accuracy.

e. What were the purposes of the meetings?

40. Post the Archer Inquiry, meetings were to press the Government to implement the Lord Archer's recommendations. I can't remember exactly the purpose or ask in each meeting. As far as I can recall most, if not all, meetings in my time as CEO were 'post Archer Inquiry'.

f. What was discussed at the meetings, insofar as they are relevant to the Inquiry's Terms of Reference, including any response from, or assurances made by, the Government to the Society. If such assurances were made, please detail who gave the assurances and when they were provided.

41. I'm afraid I can't recall the exact detail of discussions in those meetings. They certainly made assurances that they were listening to the recommendations of the Archer Inquiry. I do also recall that at some point they expressed a desire to await the results of the Penrose Inquiry before taking action. The Society may have records of those meetings, perhaps notes or letters.

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

42. My recollection is that for the years following the Archer Inquiry we pressed for the recommendations to be implemented. This was done by putting pressure on through Parliament, mostly led by Lord Morris of Manchester, and support in the House of Lords. My recollection is that the Society supported the action to implement Lord Archer's findings and when the Government announced its response we did welcome some of the actions they took, but there was

disappointment in other areas including the establishment of yet another fund. We did also engage with the Scottish Government where there was significant willingness to hold a public enquiry. I'm afraid I am unable to recall in any further detail the decisions and actions taken by the Society and whether they changed over time.

h. 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.

43. I really can't remember occasions when the Government gave particular assurances about vCJD.

44. My recollection is that a large number of people with bleeding disorders were at risk of vCJD, although that risk was only very slightly higher than, say, people who had eaten beef in the 80s. However discovery of vCJD in a post mortem of a person with a bleeding disorder in (or around) 2010 meant that risk increased again very slightly for a particular group of people. The Department of Health asked us to write to our members about this, which we did.

i. What funding did the Haemophilia Society receive and;

45. This is a very broad question. I don't remember what types of Government funding the Society received. I have a vague recollection of a Section 64 grant. A Section 64 Grant was, for a number of years, a method by which the Department of Health to support voluntary organisations to fund specific projects. Funding generally came from a number of different sources. Funding for the Society was very tight due to the rareness of the disease and the small potential group of funders. I believe this was exacerbated but the devastating impact on the bleeding disorder community of infected blood meant that they were less able to support the Society.

j. The extent to which the funding received from the Government may have influenced the Haemophilia Society's incentive to challenge the Government?

46. As mentioned in response to question 20(i), I don't remember what types of Government funding the Society received. However, I can say that, as a CEO working with the Board and Government, funding received had no impact on the Society's vigorous campaigning to get justice for people contaminated by infected blood.

5.1 Haemophilia Alliance

[You may wish to refer to HSOC0028552 and HSOC0028559 when answering these questions]

Q21. The Haemophilia Society is a founding member of the Haemophilia Alliance which had two meetings each year with the Department of Health, as referred to in [HSOC0023057, page 27]. How were topics decided upon to raise at these meetings? How much did the Haemophilia Society contribute to the list of issues which were sent to the Department of Health? How many of the issues were those raised by members of the Haemophilia Society? During your tenure, what items were discussed at these meetings?

47. I recall these meetings were established as a result of the Archer Inquiry. I don't recall the process for drawing up of the agenda but I do recall there was representation from the community at the meetings and I think Society or the community raised most of the agenda items. I don't recall much detail of the items we discussed but I think it included supply of blood products, access to the benefits systems, current NHS services and provision of information. The Society raised the majority, of the issues and these would have based on those issues that were coming to us through the community.

Q22. How did the Department of Health respond to the issues which were raised? Were any assurances made? If so, how was it ensured that these assurances were actioned?

48. I can't recall how the Department of Health responded to the issues which were raised, whether assurances were made or, if so, how it was ensured they were actioned.

Q23. Who did the Haemophilia Alliance meet with at the Department of Health? What format did these meetings take?

49. I'm sorry I really can't remember who the Haemophilia Alliance met with at the Department of Health. I think there were likely Department of Health officials and commissioners. They were formal meetings with an agenda. I recall that we may have rotated the chair between the Alliance and officials.

Q24. In the Winter 2012/2013 HQ Magazine you stated that "We have been told that issues about access to the Skipton Fund or Caxton Foundation are not part of the Terms of Reference so we have raised these directly with the Secretary of State for Health and await his response." [HSOC0023057, page 27] Please

detail the process of raising issues that did not fall under the Terms of Reference. How did the Secretary of State respond to these issues? Was any practical action enacted as a result?

50. I have reviewed HSOC0023057, page 27. I do recall our disappointment that issues relating to the funds were exempt from these discussions. However, I'm afraid I can't recall any detail on our raising these issues, the content of any response, or whether any practical action was taken as a result. In addition this wasn't really the type of meeting envisaged by the Archer Inquiry. My recollection is that what Lord Archer had intended were meetings such as those achieved in Ireland with broad terms of reference where all matters relating to the supply and safety of blood products were discussed with Government in addition to the current state of statutory services for people with bleeding disorders. The Terms of Reference were quite restrictive.

5.2 All Party Parliamentary Group

Q25. In 2012, the All Party Parliamentary Group on Haemophilia and Contaminated Blood ("APPG") was re-established [HSOC0023057, page 3 & 31]. Please explain what the goals and priorities of the group were. How, if at all, did this differ from the initial establishment of this Group?

a. How were the goals set?

51. I'm afraid I don't recall the detail of this. The goals and priorities would have been set with the agreement of the Chair and the officials. I can't recall the detail of what all of these were. The primary goal was to achieve the main recommendations of the Archer Inquiry through the campaign on infected blood products. My recollection is that this did not differ from before.

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

52. I don't have a good recollection of this. However, I think we did try and raise the current issues affecting people with bleeding disorders within the statutory services e.g. NHS/Social Care/Benefits in addition to the campaign on infected blood products, which was the APPG's primary goal.

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

53. I think the APPG had lapsed as we had missed a deadline regarding an AGM under parliamentary rules. So it was mainly an administrative need. In addition we had a number of new MPs who were very engaged.

d. What was the involvement of the Haemophilia Society in the APPG?

54. We acted as the secretariat for the group, liaising with the Chair on developing the agenda for the meetings, sending invites for the meetings, arranging the meetings, inviting speakers and producing the minutes. It is important to note this is a parliamentary group and was run along the rules and guidelines set by parliament.

e. How often were the members of the Haemophilia Society asked to support the activities of the APPG?

55. I really can't recall how members of the Society were asked to support the activities of the APPG. However, I do recall that there were regular meetings of the APPG, which the Society supported.

Q26. Please explain what the Group discussed and achieved during the course of your tenure at the Society.

56. I can't recall all the discussions but most of the discussions concerned the contaminated blood campaign. It was through the work of the APPG and MPs that a debate on contaminated blood was held in the House of Commons which was the first time this had happened. I don't recall when that was, possibly in or around 2011.

Q27. Please outline the role and the responsibilities of the Chair of the APPG. Please identify any other key individuals in the APPG who held roles and outline what those roles involved and the responsibilities they had. Do you consider those roles to have been performed satisfactorily?

57. The Chair's role was essentially to ensure the needs of people with bleeding disorders were represented in parliament and to advise of tactics that would support those needs being moved forward. The only names that I can specifically recall were Jonathan Evans MP, Owen Smith MP, Diana Johnson MP and Jason McCartney MP. These MPs were very active on the APPG but I can't recall if they held specific roles.

Q28. In an email from Bernard Manson to yourself [HSOC0015218], he mentions that Lord Morris objected to Jason McCartney's role in the APPG as he believed that Jason McCartney intended to "neuter the APPG so that it does not trouble the government". Did you discuss this issue with Lord Morris? If so, what was your understanding as to why? Why did Lord Morris have such a concern? What actions of Jason McCartney had led to this belief? Did you agree with Lord Morris and, if so, why? If you did not agree with him, why did you not? Do you consider that the APPG was effective?

58. I do have some recollection of that email [HSOC005218]. Although I'll try and remain objective some subjective views are inevitable. It must be remembered that for many years Lord Morris has sustained this campaign in parliament with very little support from the Commons. This changed in 2010 with the intake of new and active MPs like Jason McCartney. It is my view that Jason was proactive in supporting his affected constituents. I'm not sure why Lord Morris would have held that view. Perhaps because Jason was a new MP. I don't believe it's the case that it impacted on the effectiveness of the APPG.

Q29. How often did the group meet? What constituted a legitimate meeting of the APPG and what constituted an 'illegitimate' meeting of the APPG? What were the consequences of a decision made at an 'illegitimate' meeting, as referred to in [HSOC0015218]?

59. I can't recall how often the group met. The group could only meet legitimately if it followed the parliamentary rules. I think that Lord Morris felt that the 'June meeting' was 'illegitimate' due to the fact he was an officer and had not been invited to attend. I can't remember exactly but I think we had tried to contact him but he hadn't seen the invitation.

Q30. Please explain the level of involvement the Haemophilia Society had in the 'Inquiry into the current support for those affected by the contaminated blood scandal in the UK' [RLIT0000031] by the APPG. Did the Haemophilia Society provide any resources to aid the production of the report? Did the APPG produce any other reports during your tenure?

60. I can't recall exactly the level of involvement the Society had in the Inquiry but my memory is that we provided almost all the resource in the production including writing, printing and production. This is quite normal in the production of APPG reports. I don't recall if there were any other reports during my tenure.

Q31. To what extent, if any, was the position of the APPG informed by the views of the Society's membership? Did the views of the APPG differ from the views of the Haemophilia Society Executive Committee, as you understood them

61. It is my memory that the position of the APPG was always informed by the Society's membership. It should be noted that a significant number of the APPG's meeting were held with members of the membership and community present sometimes in large numbers, approximately 30 to 40. I don't recall a time where the views of the Executive Committee and the APPG differed.

5.3 Policy on Contaminated Blood

[You may wish to refer to HSOC0010542 and HSOC0010543 when answering these questions.]

Q32. Why was the decision taken to create a policy on contaminated blood [HSOC0029699]? What was the intended purpose of the document? How was this purpose decided? Do you consider that the policy achieved its intended aim?

62. My memory is that the Society had not had such a formal policy in the past. The intention was to try and focus the Society's activity and make best use of it resources. I'm afraid that I can't comment on whether it achieved its aim.

Q33. How were policy topics decided on for inclusion in the final document? Did the members of the Haemophilia Society help to contribute to the selection of topics?

63. I do recall that we consulted on the topics but can't recall exactly how this was done.

Q34. How was the decision made to include campaigning groups in the formation of this policy? How and why were the Manor House Group and Tainted Blood chosen to participate in the formation of this policy? Were other groups consulted in the formation of or feedback on this document?

64. I don't remember how the decisions were made and why the Manor House Group and Tainted Blood were specifically included, beyond them being the largest groups, but my recollection is that we consulted widely. We may not have reached all those who wished to input but I would say that, from my arrival to leaving the

Society, the campaign community was extremely fractured into groups and individuals.

Q35. What form was the practical commitment to the Manor House Group and Tainted Blood intended to take? Did this materialise in the way in which it was intended? If not, please explain what did materialise and why it was different to that which was intended.

65. I'm sorry I can't recall what form the practical commitment to the Manor House Group and Tainted Blood intended to be taken, whether that materialised in the way in which it was intended, and if not, why this was different to that which was intended.

Q36. Was the final version of the Contaminated Blood Policy sent to the Government? If so, who was it sent to? How did they respond? If a response was provided, how did such a response influence the subsequent actions of the Society?

66. I'm sorry I can't recall whether the final version of the Contaminated Blood Policy was sent to the Government, who it was sent to (if anyone), how the responded (if at all) and/or if any response influenced the subsequent actions of the Society.

Q37. How was the document received by the members of the Society? How was the document received by other campaigning and haemophilia groups?

67. I can't recall how the document was received by the members of the Society or other campaigning and haemophilia groups. .

Q38. How did campaigning efforts proceed after the publication of the Contaminated Blood Policy?

68. It's difficult to recall how campaigning efforts proceeded after the publication of the Contaminated Blood Policy, but the campaign remained at the forefront of the Society's work.

Q39. Please provide detail on the Contaminated Blood Support Group. Who did it consist of? What was the purpose of the Group? What were the aims and objectives of the Group? How did it communicate with its intended audience?

69. I'm very sorry I don't remember this group, who it consisted of, what it's purpose was, what the aims and objectives of the group was or how it communicated those with its intended audience.

5.4 Coalition for Blood Safety

Q40. Please explain what the goals and priorities of the Coalition for Blood Safety were [ARCH0000420], including your answers to the following:

a. How were the goals set?

70. As above, I'm afraid I don't remember this group and so cannot advise on how the goals were set.

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

71. As above I'm afraid I don't remember this group and so cannot comment on what extent, if any, the Coalition achieved its goals during my tenure.

c. What was the level of involvement of the Haemophilia Society in the Coalition?

72. As above I'm afraid I don't remember this group and so cannot comment on the level of involvement of the Society in the Coalition.

5.5 Campaign for an Independent Public Inquiry

Q41. During your tenure, what role, if any, did the Haemophilia Society play in seeking an independent public inquiry? Please set out chronologically the Society's campaign and or involvement in the campaign for a public inquiry. Please include:

73. It is difficult to set out chronologically the Society's campaign and/or involvement in the campaign for a public inquiry. However, I have done my best to include the information in response to the questions (41 (a) – (j)) below.

a. How the Haemophilia Society decided on the policy approach to take, including the degree to which members were consulted and the extent of which the campaign was informed by the views of the Society's membership.

74. The policy approach was always informed by the membership some of whom wanted a public inquiry. It is my recollection that not all members supported that aim. My recollection is that after the Archer Inquiry the focus of the Society's campaign was to implement its recommendations. In my tenure the campaign on

contaminated blood dominated the work the Society and a public inquiry was always part of that campaign but if the Archer recommendations had been fully implemented the need for the inquiry may have lessened. The Board has a responsibility to sustain the financial stability of the Association and its membership as a whole and therefore that impacted on the resources available to the campaign and its focus.

b. What the campaign's policy aims were;

75. The Society's position, as I recall it, was that if the recommendations were implemented this would reduce the need for a public inquiry and therefore this was the focus of the campaign policy aims in the years following the Archer Inquiry.

c. Whether those aims changed;

76. The aims didn't change as I recall, but the Society was very active in pursuing a public inquiry in Scotland at the same time, when it was clear there was a political will.

d. Who was responsible for the day to day running of the campaign;

77. During my tenure it was my role to be responsible for the day to day running of the campaign, supported by the Board.

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

78. There were a large number of actions taken by the Society. These included direct contact with Ministers, public protests, letters to Downing Street and public APPGs. We achieved debates in parliament were constantly pressing successive Governments for justice for those affected by contaminated blood.

f. Whether the aims of the Haemophilia Society's campaign differed from the aims of campaigns led by other organisations, pressure groups or campaigners campaigning for a public inquiry. If so, please describe how the Haemophilia Society's aims differed from the aims of these groups.

79. It's difficult to exactly recall the differences in aims of the Society's campaign and those of other organisations. However, during my time there were regular conflicts between the Society's approach to the campaign and those held by external campaign groups and individuals. It is my recollection that those differences were

more the tactical approach than the aims themselves. In fact, the views of those groups and individuals varied significantly. As mentioned elsewhere in my statement, over time the campaign had become extremely fractured. Although we didn't always succeed myself and colleagues worked hard to develop relationships with all key players in the campaign.

g. Any obstacles the Society faced in achieving those aims including, but not limited to, internal disagreements within the Society and disagreements with organisations, pressure groups or campaigners campaigning for a public inquiry.

80. This was an extremely emotive and complex campaign and over the seven years of my tenure there were a number of external and internal disagreements. This was almost inevitable given successive Government's inadequate response to the disaster and a lack of engagement over a number of years.

81. One obstacle I would highlight was the division between those infected by HCV and those infected by both HCV and HIV. The inequitable Government response to the two infections was responsible for much of this.

h. Whether the Haemophilia Society's campaign aims changed as a result of its interactions with organisations, pressure groups or campaigners.

82. I can't recall specific examples but the aims will have changed as the nature of the campaign changed and some of those changes would have been driven by the interactions with organisations, pressure groups and campaigners.

i. Whether the Haemophilia Society's campaign aims changed as a result of its interactions with UKHCDO members.

83. No the Society's aims did not change as a result of its interactions with the UKHCDO members. We maintained a strong link with the UKHCDO but this was to ensure the provision of good quality services for people affected by bleeding disorders.

j. What the response of the Government and/or civil servants was to the campaign, including whether the Society was given any assurances by the Government and/or civil servants 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;

84. I'm sorry I can't recall the detail of any assurances, what they were, when they were given and by whom. I can't recall the detail of any Government responses. I can't recall, but a negative or positive response would have impacted on our approach. I'm unable to recall any examples or provide any further detail on how an assurance would have impacted on approach.

Q42. Please detail what occurred between the UK Haemophilia Society and the Haemophilia Society Scotland in relation to the campaign for a UK Government Inquiry which led to resignation of the Scottish Management Committee [STHB0000405]. Please detail the impact of this change on both organisations.

85. I can't recall the exact detail of what occurred between the UK Society and the Haemophilia Society Scotland in relation to the campaign for a UK Government Inquiry, which led to resignation of the Scottish Management Committee. I do remember that the Scottish Management Committee became disillusioned about the commitment of the Society's Board to the Inquiry in Scotland. This led to a number of disagreements between members of the Society's Board and the Committee. It certainly made it more difficult for the Society to liaise over the approach to the Inquiry but my colleague Dan Farthing (Communications Manager) and I worked hard to maintain that liaison.

Q43. 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 HSOC0003661 and HSOC0023072, page 12 to assist you.]

86. The Society was actively involved in the push for an Inquiry including attending several meetings with Nicola Sturgeon, then Minister for Health and Wellbeing. When the Inquiry took place the Society committed a member of staff to attend all the hearings. I recall that the approach was collaborative with the Haemophilia Society Scotland.

5.6 Other campaigning

Q44. Following from 5.5, Please state all other campaigns relevant to the Terms of Reference that you were involved in while at the Haemophilia Society, and provide a brief description of each, insofar as they are not addressed elsewhere. These might include:

a. Financial support for HIV

b. Financial support for HCV

c. Campaign for non-interferon based therapy for HCV

d. Campaign for recombinant blood products

87. Financial support for HIV (a) and Financial support for HCV (b) are probably covered by the aims previously mentioned. I do recall some work with hepatitis campaign groups to achieve non-interferon based therapy for HCV (c). However, I don't recall the detail.

88. The Campaign for recombinant blood products (d) is quite complex and I don't remember the details. However, in my time the Society was involved in ensuring access to recombinant products for people with bleeding disorders. Some rare blood disorders were treated with plasma-products. In some cases I recall patients preferred the plasma product to the recombinant as they felt it was more effective. The Society worked closely with EHC and WHF to ensure the safety and supply of these products.

5.7 Interactions with other campaign groups and charities

Q45. Insofar as not already covered in your responses, please state all organisations, pressure groups or campaign groups which the Haemophilia Society interacted with on issues that are relevant to the Terms of Reference. Amongst others, this should include the Contaminated Blood Campaign Coalition, the Birchgrove Group, the Tainted Blood committee, the Manor House Group and the Factor VIII Campaign Group. In your answer, please provide a description of your relationship with each group, including:

a. The level of support the Haemophilia Society provided to these organisations and charities, if any.

89. I'm not entirely sure what support means here. We didn't really provide any administrative or financial support to these organisations, pressure groups or campaign groups, although we did arrange meetings of the groups and individuals.

b. Any issues which the Haemophilia Society and these groups disagreed on. If so, please describe the nature of the disagreement in as much detail as possible.

90. There were always a number of different views on approach and tactics. I seem to recall that not everybody felt an independent inquiry was the best approach and

certainly there wasn't full agreement for support for the Archer Inquiry's recommendations. I cannot recall what the alternative views entailed.

c. ***Any attempts to consolidate the work of the campaign groups and how successful those attempts were.***

91. We held a number of meetings over the seven years I was CEO sometimes with all the groups and sometimes with a smaller number. I and my colleagues had regular contacts with the key campaigners. My view is that it would have been almost impossible to consolidate all the work of the campaign groups due the fractured nature of the campaign which existed when I arrived. However, I think in my tenure we had some success in consolidating the campaign approach and I recall some successful meetings in parliament and we held a number of meetings of with campaigners which whilst difficult did enable us to agree on approach and tactics.

d. ***Please describe the Haemophilia Society's relationship with haemophilia organisations and charities in Wales, Scotland and Northern Ireland. In your answer, please address:***

i. ***The need for separate haemophilia charities for the devolved regions.***

92. I don't recall separate other independent charities in Wales and Northern Ireland, although there were active campaign groups. As CEO I kept up a regular liaison with organisations in Scotland.

ii. ***The level of support the Haemophilia Society provided to these organisations and charities, if any.***

93. I don't recall the level of support the Society provided to other organisations.

iii. ***Any issues which the Haemophilia Society and haemophilia organisations and charities in Wales, Scotland and Northern Ireland disagreed on. If so, please describe, to the best of your ability, the nature of the disagreement.***

94. As above, I don't recall any issues which the Society and organisations and charities in Wales, Scotland and Northern Ireland disagreed on.

Section 6: Interaction with Trusts and Schemes

Q46. During your tenure, what was the Haemophilia Society's position, if any, with regards to the compensation structure for haemophiliacs who were infected with hepatitis and/or HIV as a result of contaminated blood products? If this changed over time, please detail when and why.

95. My recollection is that, throughout my tenure, the payment system and funds established were not fit for purpose and did not address the needs of those affected. Please also note that it is my memory that the Government did not use the word compensation as this suggested that there was fault in the Government's actions when the infections occurred.

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

96. The Society's position was regularly communicated to the Government. I can't recall exactly but in most cases I think they responded that it was fair and it was a good arrangement. I don't recall if this changed over time.

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

97. I don't recall what statements and assurances were made by the Government to the Society in relation to compensations during the relevant period or if this changed over time.

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

98. I don't recall if these statements and assurances were relied upon. However, I don't think I felt they were ever very reliable.

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

99. I don't recall how the Society presented the trusts and scheme to members of the Society or how it communicated the process for applying for financial aid to its members. However, we did, where we could, make sure that people who contacted us were aware of the schemes as, although they weren't fit for purpose, people needed to access them. I don't recall if this changed over time.

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

100. I don't recall how many members of the Board of Trustees or other committees in the Society were also involved in trust scheme as board or committee level. I do seem to remember the number of Society representatives on the Macfarlane Trust (MFT) Board was reduced in my time as CEO.

Q47. Please detail your involvement with the trusts and schemes in your role at the Haemophilia Society.

101. I didn't have involvement in the workings of the trusts and schemes. I tried ensure there was an open dialogue and to support where I could.

6.1 Relationship with The Macfarlane Trust

[You may be assisted by MACF0000128_032 in your answers.]

Q48. Please detail your involvement with the Macfarlane Trust, and the relationship between the Haemophilia Society and the Macfarlane Trust.

102. As mentioned in my response to question 46(e), above. I attended meetings between the two organisations and met fairly regularly with the CEO and sometimes the Chair of the MFT.

Q49. Please outline the role that the Haemophilia Society played in the operations of the Macfarlane Trust. To what extent, if any, did you or other members of the Haemophilia Society have an influence over the running, functions, processes, aims or objectives of the Macfarlane Trust?

103. The Haemophilia Society did not play any part in the operations of the Macfarlane Trust. Although the Society provided a number of trustees, their role as trustees, and the decisions they took as trustees of the MFT were independent from the Society. The influence of the Society on the running, functions, processing, aims or

objections of the MFT did not extend beyond providing feedback from our members on the processes of the Trust. The Society did support the events for beneficiaries run by MFT.

Q50. Please confirm if you attended Macfarlane Trustees meetings and any other(s) you attended and, if so, please also confirm your role at those meetings. If you were a trustee, please explain how you came to be appointed and for what period you were in that role?

104. I wasn't a trustee of the MFT. I can't recall if I was ever asked to be 'in attendance' a MFT trustee meeting. My role was to represent the views of the Society and its members to the MFT.

Q51. How often did the Haemophilia Society and the Macfarlane trust meet? Please detail how often the two organisations communicated.

105. There was regular communication (to the best of my recollection, approximately 3 to 4 times a month) but I can't recall how many formal meetings there were.

Q52. Please detail the overlap between the Macfarlane Trust and the Haemophilia Society, including the overlap in personnel, roles and responsibilities. Do you consider that there was a sufficient level of separation between the Macfarlane Trust and the Haemophilia Society to ensure that each organisation adequately supported its recipients and members respectively?

106. I consider that that there was a sufficient level of separation between the MFT and the Society. I don't recall any overlap in personnel, apart from trustees, between the MFT and the Society. A volunteer worked for the Society in a support capacity and ran the MFT events for a number of years.

Q53. 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.

107. I'm afraid I can only recall that a number of trustees were nominated by the Society. I cannot provide any further detail on the appointment process for the MFT, the composition of the board or whether this changed during my tenure.

Q54. Did the Macfarlane Trust reject any of the nominations for Trustee from the Haemophilia Society?

108. I'm afraid I can't remember if the MFT rejected any of the nominations for Trustee from the Society.

Q55. 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?

109. The relationship between the MFT and the Society was always strained, as MFT were a 'not fit for purpose' Government body distributing funds to many of our members. We raised a number of issues over the years and the MFT did their best to resolve them. It is my recollection that most issues related to beneficiaries treatment by the Trusts and in particular applications for discretionary payments. I can't recall exact details but at times I think relationships between the beneficiaries and the MFT staff and Board were strained. I tried to maintain a good relationship with the MFT CEO, which overall I hope was beneficial to people with bleeding disorders.

Q56. 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?

110. I can't give an accurate assessment of this question as I wasn't close enough to the day to day running of the MFT. I had the impression the MFT had a certain amount of independence from the Government/ Department of Health but there were certain boundaries in which it could operate.

6.4 Relationship with other trusts and schemes

Q57. Please detail the relationship between the Haemophilia Society and the remainder of the Alliance House Organisations ("AHOs"), namely:

a. The Caxton Foundation;

111. I can't recall the relationship between the Society and the Caxton Foundation.

b. The Skipton Fund;

112. I can't recall the relationship between the Society and the Skipton Fund.

c. The Eileen Trust; and

113. As far as I can recall, there was no relationship between the Society and the Eileen Trust.

d. The Macfarlane & Eileen Trust.

114. To the best of my knowledge, and as far as I can recall, there was no relationship between the MFT and the Eileen Trust.

Q58. Please detail the opinion of the Haemophilia Society membership on the efficacy of the above mentioned AHOs

115. It's very hard to speak on behalf of all the Society members, but certainly some members were extremely unhappy at times about how funds were distributed and how decisions were made. I recall that there were some discretionary payments and it is my recollection that that it was the decisions on whether to award these that caused some disagreements.

Q59. 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.

116. No the Society did not have a similar level of involvement with the other four AHOs as it did with the MFT. The main relationship was with the MFT due to the way it was set up and its governance. I don't remember exactly how the Caxton Fund was established and how we engaged with it.

Q60. Please comment on any difficulties or shortcomings you encountered with the trusts and schemes during your time at the Haemophilia Society.

117. My main comment is that the Funds were not fit for purpose. They caused division by separating the infections of HIV and HCV and not treating the beneficiaries as individuals. They were under-resourced and stuck between the Government and

the beneficiaries. Overall, I think the staff team tried its best but there were clearly times when they fell short.

Section 7: Financial Activities

7.1 Fundraising Activities

Q61. How, if at all, did the Haemophilia Society's fundraising activities develop over your tenure?

118. Funding was always a challenge for such a small organisation. We tried with a small fundraising team to use a number of channels, community, trusts, corporate and appeals. The resource was reduced by a restructure in 2007/8 driven by a lack of funds early in my time as CEO. This reduced resource restricted our ability to build secure income streams as we reduced our fundraising capacity from three staff to one.

Q62. What proportion of the budget of the Haemophilia Society was raised through fundraising during your tenure?

119. I really can't recall what proportion of the budget of the Society was raised from fundraising during my tenure. However most of the income was through fundraising of one form or another e.g. community, major donors or companies.

Q63. Were Society members aware of where the money they raised or donated was being spent?

120. Yes Society members were aware of where the money they raised or donated was being spent. This would have been explained in the annual report and at the AGM. I can't recall specific examples we would have reported our spend on specific activities.

7.2 Relationship with Pharmaceutical Companies

Q64. To what extent did the Haemophilia Society rely on financial contributions from pharmaceutical companies manufacturing and/or supplying blood products? In your answer, please provide as much detail as possible on any of the Haemophilia Society's activities, publications, appointments and staff that were funded or partially funded by financial contributions from pharmaceutical companies. Please describe the level and nature of funding that was being provided when you commenced your tenure at the Society and how that changed, if at all, over time.

121. I can't recall all the detail of the reliance by the Society on financial contributions from pharmaceutical companies manufacturing and/or supplying blood products. I think the financial contributions increased over my time as CEO as they were a major source of income. The funding was always under the strict guidelines of the Association of British Pharmaceutical Industries (ABPI). This restricts what the funding can be used for, so in many cases they were unrestricted funds, but occasionally funded specific activities such as holidays for children.

Q65. 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.

122. As CEO I was responsible for the relationships with the companies and their support. I was in most cases the only point of contact. Methods of communication between companies sometimes with individuals in smaller companies and sometimes meetings with the companies and their representatives.

Q66. Was the Haemophilia Society allowed to determine where the funds from the pharmaceutical companies were directed, or was the money given for a specific purpose? What, in your view, were the motivations or expectations, if any, of pharmaceutical companies who donated to the Haemophilia Society? Was there an expectation that the Haemophilia Society would provide anything in return and if so, what?

123. The Society was always the determiner of whether to accept the donation and where it was directed. On occasion a company might have a particular initiative which would benefit patients but was not directly related to their product (e.g. holidays for children). Like all pharmaceutical companies for any disease they are in a very competitive market and it is helpful to them to have good relationships with patient groups. I think all companies would want to see some tangible benefit from the relationship but this is strictly controlled by ABPI guidelines.

124. It's my recollection that the companies did not expect anything in return.

Q67. 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?

125. The larger companies with a larger share of the market were more active and made larger donations. Some of the companies were very small and had either a very small market share or a niche product. I don't think this affected their expectations of the Society. There were some companies who had an interest in specific areas. For example, one I remember was Novo Nordisk who wanted to support initiatives for young people with bleeding disorders.

Q68. A number of the Haemophilia Society Haemophilia Quarterly issues ("HQ") ended with thanking a range of pharmaceutical companies for their "valuable support" including Baxter Bioscience, Bayer, CSL, Behring, Grifols, Novo Nordisk, and Pfizer Pharmaceuticals [e.g. HSOC0023056, page 40]. Was that record a requirement of their funding? What was agreed in this regard? If so, how was this agreed?

126. I would normally agree with companies the level of acknowledgement for their contributions. This was mostly driven by ABPI guidance where companies are required to declare transparently their support. This guidance became much tighter in the period that I was at the Society.

Q69. Did the Haemophilia Society publish or disseminate any articles or publications in exchange for or with the expectation of receiving financial contributions, or any other benefit, by pharmaceutical companies? If so, please provide details of the nature of these articles or publications.

127. I don't recall this ever happening. The only thing I can recall is that we may have reported on activities such as a holiday for children or a project that a company will have supported and we would be required to acknowledge that support by the guidance.

Q70. Did the Haemophilia Society refrain from publishing or disseminating any articles or publications in exchange for or with the expectation of receiving financial contributions, or any other benefits, from pharmaceutical companies? If so, please provide details on the nature of these articles or publications.

128. To the best of my knowledge and recollection the Society did not refrain from publishing or disseminating any articles or publications in exchange for or with the expectation of receiving financial contributions or any other benefits from pharmaceutical companies.

Section 8: Variant Creutzfeldt-Jakob Disease

Q71. Please detail the relationship between the TSE Risk Assessment Sub-Group and the Haemophilia Society. [You may wish to refer to HSOC0023058, page 29 to assist you.]

129. I have very little memory of this group and so cannot provide detail of the relationship between the TSE Risk Assessment Sub-Group and the Haemophilia Society.

Q72. How much communication did the Haemophilia Society have with the TSE Risk Assessment Sub-Group? What were the Haemophilia Society's particular concerns or issues that were relayed to the TSE Risk Assessment Sub-Group? What was the TSE Risk Assessment Sub-Group's response to that communication from the Haemophilia Society?

130. I'm afraid I can't recall how much communication the Society had to the TSE Risk Assessment Sub-Group, what the Society's particular concerns or issues were that were relayed to the TSE Risk Assessment Sub-Group, or what the TSE Risk Assessment Sub-Group's response to that, if any.

Q73. In relation to vCJD, the Society raised the idea of pre and post-test counselling [HSOC0023058, page 29]. Was this idea presented to any member or representative of the Government? If so, what was the response?

131. I can't recall whether this idea was presented to any member or representatives of the Government. I do not recall a response, if any was received.

Q74. Please describe any and all efforts made by the Haemophilia Society to campaign or advocate for issues associated with vCJD. [HSOC0011207 may assist in your answer].

132. I can't recall detail of any efforts made by the Society to campaign or advocate for issues associated with vCJD. However, vCJD certainly was included in many of our representations to Government and campaigning work. We also took up with the Department of Health individual cases of people considered at risk of vCJD who had faced discrimination including having their operations cancelled at short notice.

Section 9: Other Issues

Q75. Please describe the circumstances around your departure from the Society.

133. I had spent seven years as CEO and I felt that the time was right to move on in my career.

Q76. 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?

134. To the best of my knowledge, no Society staff or committee-members purposefully or unintentionally destroyed documents relevant to the Terms of Reference of the Inquiry.

Q77. 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.

135. I was very humbled to have played a small part in the campaign to get justice for people infected by contaminated blood and I'm very sorry that I've not been able to remember many things that happened in my seven years as CEO.

136. I was appalled and saddened that, as well facing the devastating the impact of the disaster, many people had to spend the rest of their lives campaigning for justice and public inquiry. With exception of the odd supportive minister and official successive Governments showed a complete lack of empathy over many years. A desire not to admit fault for the disaster was, I believe, a huge contributor to this.

137. By the time I took over as CEO I think the Society had been severely impacted by the campaign. As I've stated in my statement above the campaign had fractured and the Society tried to help support the co-ordination of the campaign. The Society in my time had very little resources and was trying to support both the campaign on infected blood and the on-going needs of people with a wide-range of bleeding disorders of all ages. It is inevitable that it couldn't sustain all of these things all the time.

138. I'd like to pay tribute to Lord Morris of Manchester who, in my view, waged an almost single-handed campaign over many years with the support of a small number of colleagues in the Lords. That said the work of Owen Smith MP, Norman

Lamb MP, Jason McCartney MP and of course Diana Johnston MP in the last ten years that did a huge amount to achieve this Inquiry.

Statement of Truth

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

Signed **GRO-C**

Dated 26/08/2021