Witness Name: Robert Anderson Cowe
Statement No: WITN3647001
Exhibits: WITN3647002
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WITN3647007
WITN3647008
Dated: 28 April 2021

**INFECTED BLOOD INQUIRY**

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**WRITTEN STATEMENT OF ROBERT ANDERSON COWE**

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I, Robert Anderson Cowe (known as Andy), of GRO-C GRO-C will say as follows: -

1. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 November 2020. I set out my evidence under the headings supplied by the Inquiry's legal team for ease of reference.

**Section 1: Introduction**

2. My date of birth is GRO-C 1952.

3. I attach a copy of my CV at WITN3647002.

4. I am a member of the Haemophilia Scotland group although I cannot be sure as to when I chose to become a member. The CEO of Haemophilia Scotland informs me that I have been a member since its inception as a charity in 2012. I have occasional contact with the CEO, Dan Farthing but I have not played any active part in the organisation, except in relation to a current fund-raising initiative.

5. I am a member of the Scottish Infected Blood Forum organisation and at the invitation of the then Chairman, the late Philip Dolan, I was elected Treasurer in 2013. I played a very active part in the management of the organisation until my resignation in 2016.

**Section 2: Previous Evidence**

6. I have not provided any evidence nor 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. I have never wanted to have to relive these times of my life.

**Section 3: My role and the structure of the Haemophilia Society**

*Q5. When you joined the Haemophilia Society, what were the objectives and functions of the Society? If these changed over time, please detail when and why.*

7. I cannot state when I became a member of the Haemophilia Society ("the Society"). My mother joined the Society after I was diagnosed with haemophilia at around the age of 18 months, possibly at the end of 1953 or the start of 1954. She became Secretary of the Scottish Group of the Society and remained so for many years, so I grew up hearing about the Society and attending its meetings. My late wife succeeded her as Scottish Group Secretary, although the group may have been known as the South East Scotland Group by that time. At different times I held the posts of Chairman and Treasurer of the South East of Scotland Group.

8. My memory for dates and details of past events, especially those that took place some 35 years ago, is not good. The documents I have received as part of this Rule 9 request have reminded me of people, sub-committees and working groups that I served with and on, and meetings that I attended, of which I have absolutely no recollection now. I was very actively involved and deeply committed at the time, but after my time with the Society I left all that behind to concentrate on other aspects of my life. My difficulty in recalling details of Society work without the prompts in the documents I have received will become all too apparent in my answers to questions later in this statement. When I left the Executive Committee, I closed the door on that part of my life to concentrate on a new set of activities.

9. I could not articulate the formal objectives and functions of the Society when I first became involved with it. As stated above, I grew up with the Society as part of my life. My personal perception was that it was about providing information and support to people with haemophilia and their families, and representing their interests to the medical profession.

10. As time went on and I became more aware of resourcing issues, I saw a role in promoting the importance of good haemophilia treatment to the NHS and government agencies. These were different times and the current practice of offering or requiring new company directors or charity trustees to have a formal induction process did not exist then.

11. As to how the objectives and functions of the Society changed over time, I do not think the fundamental objectives changed over time, but clearly, the priorities changed to meet the needs at any particular time. Once again, I rely on the documents made available to me to prompt my memory and I note that the Society employed consultants on at least two occasions to assist in reviewing the Society's structure and operations. In 1989 the Charities Effectiveness Review Trust (CERT) was engaged to carry out an independent review of the organisation. I remember contributing to its research. Its general findings are reported in the Bulletin dated March 1990 (WITN3647003), having been discussed and approved in late 1989 by the Executive Committee and Council. The Bulletin article noted that the CERT found that the Society was "*effective, active and successful in meeting the needs of people with haemophilia*", but *"recommended a complete overhaul of [the Society's] organisational structure, committees and decision-making.*" (page 8 of WITN3647003). The Bulletin article goes on to note that the CERT findings were discussed at the Chairman's Conference in November 1989 and "*the decisions made at the Conference marked the start of a programme of development and growth which will take time to come to fruition*" (page 9 of WITN3647003). Without reference to the CERT report or the notes of the Chairman's Conference I cannot recall any of the further detail of the CERT recommendations, nor the actions taken by the Society in response. I authored the report that was published in the March 1990 Bulletin.

12. I see from Executive Committee minutes dated October and November 1991 (my bundle documents 6, HSOC0010385 and 7, HSOC0010387) that the Society revisited the question of its strategic management with assistance from the Compass Partnership, although I regret that I have no memory of the discussions or the conclusions. One of the recurring themes seems to have been the relationship between the local groups of the Society and the national office. I think some of the local groups felt their needs were neglected by the Society, while some on the Executive felt the local groups served little purpose and distracted the Executive from other priorities.

*Q6. Please confirm the dates of your executive roles at the Haemophilia Society and explain what your role and 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 Haemophilia Society's publications.*

13. In my later teenage years, I was elected to the Scottish Group Committee of the Society and in my twenties, I started attending the Society meetings in London as the Scottish Group's representative. (Over time, the Scottish Group evolved into separate groups in Grampian, Perth, Tayside, South East Scotland and West of Scotland groups). I cannot remember a time of my life when I was not a member. I remain a member although I have played no active part in the Society since leaving the Executive Committee in 1997 when my term of office expired at the 1997 AGM (I was returned as a trustee at the AGM

in 1996 and served in that capacity until the AGM in 1997). I attended the virtual AGM in 2020.

14. While I was utterly dedicated to the cause of the Haemophilia Society in those years, it was only one part of my life as I was busy building my career, advancing in my professional body (ICSA The Chartered Governance Institute) and trying to have a family life. The Executive Committee met monthly in London, usually in the early evening, and to attend these meetings I would arrange to leave work early, fly from Edinburgh to London, attend the meeting, and, if I was lucky, get a late flight back to Edinburgh, or if not take the sleeper train home so that I was in place for work the next day. Many weekends were spent at Society residential meetings, and in addition, as an active Executive Committee member based in Scotland. I would often attend meetings with local groups of members in Glasgow, Dundee or Aberdeen. While my travelling expenses were reimbursed, my time was given voluntarily and I was fortunate that my late wife was so understanding about my frequent absences on Society business. Because evening meetings and, later, some afternoon meetings involved considerable juggling of my diary and work commitments there were occasions when I had to send apologies for absence.

15. Initially attending Council meetings as a regional group representative, I was drawn into more active involvement in the Society nationally, particularly after the appointment of David Watters as Coordinator (later General Secretary). I was elected to the Executive Committee in 1986 and became Vice-Chair between 1990 and 1992. I probably became publications editor sometime between 1986 and 1988. I remained on the Executive Committee until 1997 when my term of office expired.

16. I cannot state what my specific role or responsibilities were as an Executive Committee member or Vice Chair, but I observe from the minutes of meetings supplied to me by the Inquiry that I would often provide reports to the Executive Committee on the activities of the various sub-committees that I served on from time to time. However, there were no written job descriptions - it was simply a case of doing what one could to help the Society in whichever aspect of the work needed doing. I was not infected with HIV, I had an understanding of the management of charities as I was a qualified chartered secretary and lectured in business and management. I was also used to writing documents and public speaking, and I suppose it was for those reasons I was invited to stand for election as Vice Chairman. As Vice Chairman I would have been expected to deputise for the Chairman if required, but that eventuality never arose.

17. It is very important to bear in mind that the Society was not a big organisation. It was not a huge charity with a formal divisional structure. The Executive Committee consisted of 12 members who were all volunteers, and all (with one possible exception) had a personal or familial connection to haemophilia. We shared a common understanding of

the problems of haemophilia and were all committed to doing whatever we could to support the charity and our members. The various sub-committees and task groups would occasionally pull in members of local groups of the Society, however the sub-committees and task groups largely consisted of the 12 members of the Executive Committee. There were formal reporting methods in place where the various sub-committees and task groups would report to the Executive Committee, but we were not a big organisation and all members of the Executive Committee would likely have had a general awareness of all the activities being carried out.

18. I am indebted to the Haemophilia Society for providing me with a record of the dates I have cited of my appointments (taken from minutes of the Society's AGMs and confirmed by a spreadsheet supplied to me by Debra Morgan of the Haemophilia Society at exhibit WITN3647007). As can be seen from the documents provided by the Inquiry team there were many meetings covering different topics at different times. Members were assigned to or volunteered for different roles at different times. A significant proportion of the Executive Committee were personally affected by HIV and AIDS and the time and energy they could devote to the work of the Society varied with their state of health. It was because of the previous editor, Clive Knight GRO-A invited me to take over as publications editor.

19. I was editor from, I think, 1988 - 1997, responsible for editing The Bulletin, which was the quarterly members' journal, and a range of information booklets. So far as the quarterly Bulletin is concerned, I would have discussions with David Watters about what was current in the world of haemophilia, and we would agree who should be approached to write articles for publication. We employed a professional publishing house to set the copy and the Society provided me with a fax machine and a dedicated telephone line so that I could receive the copy, proof-read the text and suggest amendments to layouts before signing it off for printing.

20. I usually wrote a short editorial, but (with the exception of the report on a World Federation of Haemophilia ("WFH") meeting held in Stockholm in 1983 which I attended as a group representative, and the summary of the CERT report in the Bulleting of March 1990), I don't recall writing articles personally for the Bulletin, although with the passage of time I can't swear that I didn't. As I remember, the editorial column usually highlighted or summarised the major issues facing the Society, or was a "plug" for the other articles in the Bulletin. David Watters and I would discuss the content for the Bulletin. I was always keen to ensure that we had a "heavyweight" medical or scientific article (I felt this lent the Bulletin credibility with the professional audience); some content more relevant to the treatment of patients e.g. profiles of treatment centres or physiotherapy, and news items about fundraising, local group activities and personal stories. I tried to include features that would be "self-sustaining" e.g. a series of profiles of Haemophilia Centres or local groups of the Society that would run over several editions of the Bulletin as way

of ensuring that some pages were filled relatively easily as well as keeping the audience engaged. David Watters had a wide network of contacts and this was invaluable in identifying and approaching likely contributors. My aim was to make the Bulletin attractive to as wide a range of readers as possible. I instigated the process to have Society publications allocated an ISBN or an ISSN number to enhance our reputation and credibility, as it allowed our publications to be referenced and identified as recognised publications.

21. So far as the information sheets and booklets were concerned, we followed a similar process. I do remember authoring or at least revising some of the content of a revised edition of "Introduction to Haemophilia" booklet although I cannot now attach a date to that edition and I no longer have a copy. I do not recall whether a clinician would have reviewed the final document, but the content would have been based on the output of Society meetings and seminars and may have also been informed by Dr Peter Jones's book 'Living with Haemophilia'. Our largest one-off project was the production of "Haemophilia, HIV and Safer Sex" booklet and I vaguely remember attending a meeting of a multi-disciplinary group comprising authors (one of whom was my late wife who was also a nurse working in an AIDS ward around that time), designers, illustrators and probably the publisher.

22. I have been asked for information on the different sub-committees, task groups and advisory bodies that I might have been involved in and to describe the purpose, functions and responsibilities of each committee, task group and advisory body. I find this question impossible to answer in any detail. As already stated, I was willing to help the Executive Committee as a whole in whatever capacity I could. Sub-committees and working groups came and went over time. I do not recall any formal process of specifying roles and remits. The Executive Committee was a small group of dedicated individuals, 12 volunteer members, who worked closely together and there was a lot of common understanding of the issues of the day. Different members had different strengths and areas of interest and membership of these sub-groups tended to reflect that.

*Q7. Please list all the different Haemophilia 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. Please include a description of the Publications and External Relations Working Party, Grants Committee, Policy Committee, Services Committee, the Hepatitis Task Group and the extent and period of your involvement.*

23. I have been specifically asked to list and detail my involvement with five named committees or working parties, namely:
    a. Publications and External Relations Working Party,
    b. Grants Committee,
    c. Policy Committee,

d. Services Committee, and
e. the Hepatitis Task Group

24. Without the information contained within the Rule 9 request and the accompanying documents I could not have identified any of these committees and groups from my own memory. It is clear from the minutes of various meetings that I did play a part in those committees, but beyond what is recorded in the minutes, I cannot now remember exactly what my role was. I did whatever I could to help the Society in whatever capacity I was asked. I may have been involved in other groups that I cannot now identify.

*Publications and External Relations Working Party*

25. I have dealt with my role in publications above, and I cannot remember when External Relations became part of the title. I may be mistaken but I think it was when the Executive Committee gained a member whose professional expertise was in the field of public and press relations, along with the need to manage the Society's response to the increased media interest in blood borne infections. After hearing some of the evidence from David Watters, I was prompted to remember the relationship with GJW Government Relations, which was a lobbying firm involved in the HIV campaign, but for myself I had forgotten their involvement. Aside from my involvement in publications set out above, I cannot recall the detail of the work carried out by this Working Party, but I do recall being provided with a pager and there was a rota of people who were on "press duty" to answer enquiries about haemophilia and the HIV campaign. I do not remember attending any meetings with GJW but it is possible that I met Rory Chisholm (one of the GJW staff) in the Society's office. Living in Scotland, I was not on hand to attend meetings during normal working hours which meant I was necessarily remote from a lot of these meetings. Although I have destroyed all my documents from my Haemophilia Society days, I still have my appointment diaries and I see a few entries where I have received a pager message to call a newspaper and I have noted the relevant telephone number in my diary. I do not now have any recollection of the content of these calls.

*Grants Committee*

26. I have no idea of the dates I was a member of the Grants committee, but I think it was in the earlier days of my involvement with the Society. I think we moved away from trying to be a grant awarding body for research activities (they became more expensive than we could afford.) I do remember receiving grant application documentation and I am grateful for the document supplied by the Inquiry recording a discussion about grant allocation meeting. As I recall, we tried to channel funds to projects that we judged to have most immediate impact on our membership, rather than more theoretical or long term research. I recall receiving a telephone call at home one evening from Professor Ludlam who wanted to sound me out informally about the likelihood of a potential

application meeting with approval. I cannot recall the substance of the conversation, but I know I would have been very circumspect in giving any advice about the success of his application.

*Policy Committee and Services Committee*

27. Once again, I have no clue about the dates of my membership or the substance of any meetings other than that contained in the documents supplied to me.

*Hepatitis Task Group*

28. Clearly I was a member of this group but I have no recollection of its meetings, other than that I did not feel comfortable in this group as I did not regard myself as sufficiently knowledgeable on the subject to make a viable contribution.

29. When I left the Executive Committee in 1996, I closed the door on that part of my life. I was advancing in my career in the University and becoming more deeply involved with my professional body, the Institute of Chartered Secretaries and Administrators (now the Chartered Governance Institute). I kept a substantial volume of paperwork from my time with the Society until 2010 (I had a three drawer filing cabinet crammed with papers). In 2009 my first wife died after three years' illness with breast cancer. In 2010, I downsized into a new home and disposed of most of my records believing I would never need them again and they were an unwelcome reminder of a life I had left behind. I kept a few documents as "souvenirs" although I cannot now remember on what basis I selected those to keep.

30. In 2010, Professor Christopher Ludlam contacted me to ask if I had any Haemophilia Society publications or minutes that he might see in order to help him in his preparation for the Penrose Inquiry. Prof Ludlam was my consultant at Edinburgh Royal Infirmary Haemophilia Reference Centre from the time he arrived as Centre Director until his retirement. I knew him in our patient/doctor relationship and we met in my Haemophilia Society capacity. For example, when the Centre was relocating to a new part of the old city centre hospital he invited me to discuss the move and we occasionally attended the same fund-raising events. My late wife was a nurse (although in different hospitals from Prof Ludlam) and occasionally she would have to liaise with him over patients for whose treatment they shared responsibility. I always had a cordial professional relationship with Prof Ludlam (outside the consulting room we were on first name terms) so I gladly sent him the last of my records and invited him to dispose of them as he wished. In February 2011 I unearthed a few more documents and sent them on to him. I found that final farewell to my involvement with the Society quite therapeutic. With downsizing into a small house after my first wife's death, I saw no need to hold on to paperwork that belonged to a closed chapter of my life.

### 3.1 Medical Advisory Panel ("MAP")

*Q8 To the best of your knowledge, please describe the purpose, function and responsibilities of the Medical Advisory Panel. If this changed over time, please set out this information according to applicable time frames*

31. The only way I have of answering this question is by reference to the documents supplied to me. I had no role in the Medical Advisory Panel and with one recorded exception, I do not recall attending any meetings, including the one referred to in the Minutes dated 27 April 1990 (document HSOC0010954). The MAP was in existence when I became actively involved in the Society and, as I understand it, still exists to this day. I see from the documents supplied that I attended a meeting of the MAP, but I cannot remember attending this meeting or what was discussed. I find it slightly surprising that there is no record of me speaking at the meeting as I normally tried to contribute to meetings. I also note that the Society issued proposed new terms of reference in 1990/91. I may have been party to the drafting of these terms of reference, but I have no recollection of doing so.

*Q9 How did the Haemophilia Society select members of the Medical Advisory Panel? What criteria were used, if any? How did membership change over time? You may be assisted by [PRSE0000956] which sets out the membership in the 1980s.*

32. I was not personally involved in the appointment of MAP members, but based on my recollections of conversations with other members of the Executive Committee, I think there were a number of factors that would have been considered in selecting candidates for membership of the MAP. One would be the extent to which a doctor was "user friendly" (or "favoured" in the word of the 1990 document). I think different clinicians were more willing than others to be involved with, and contribute to the Society's work, and thus would be more likely to be invited to be part of the MAP. Another would be the need to have acknowledged expertise in certain areas of interest. Finally, I think there was the desire to have a geographical spread of members to ensure representation from around the country. I do not know the details of how MAP members were appointed, but I believe David Watters would have made initial contact and the Chairman would have had a final say.

*Q10 In a letter to Dr Ludlam dated 8 August 1988 [HSOC0011023], David Watters stated that "The Medical Advisory Panel has, until now, not played a major part in the life of the Society. However, it is the clear wish of the Executive Committee that this situation should change." Please explain the role of the Medical Advisory Panel until August 1988.*

33. I have no direct knowledge of how the MAP was consulted prior to August 1988, nor its role prior to 1988. Particular members may have been approached informally by members of the Executive Committee or by David Watters. From the evidence already presented to the Inquiry it appears that Professor Bloom was the primary point of contact.

*Q 11 The Inquiry understands that the Medical Advisory Panel did not meet in person until 1988 [HSOC0010470]. Please confirm whether this is true, and explain, prior to August 1988:*

*a. Who from the Haemophilia Society decided when advice would be sought from the Medical Advisory Panel?*

*b. On what matters relevant to the Inquiry's Terms of Reference did the Haemophilia Society seek the advice of the Medical Advisory Panel?*

*c. Did the Haemophilia Society seek advice from all members of the Medical Advisory Panel or only a selection of them? If a selection, how was that selection determined?*

*d. Did some members of the Medical Advisory Panel have more influence than members, and if so, who?*

*e. How was advice communicated from the Medical Advisory Panel to the Society?*

*f. How was the Medical Advisory Panel's advice recorded once it was received by the Society?*

34. I cannot recall details about the MAP and I therefore do not have the knowledge on which to answer these questions, save to say that to the extent that consultation took place with MAP, I am sure that the Executive Committee would have relied on the opinions sought and supplied.

35. Members of MAP contributed articles to the Bulletin and Update and I presume these were in response to requests made by Executive Committee members or by David Watters. I would not have personally been involved in liaising with MAP. David and I would have discussed what content to include in the Bulletin and who to approach, and David would have liaised with the appropriate individuals.

*Q12 From 1988, how often did the Medical Advisory Panel meet? Were minutes of the meetings taken? Who attended those meetings in addition to the members of the Panel?*

36. I note that the proposed MAP terms of reference provided by the Inquiry dated 7 November 1991 (document HSOC0010470) say that the Society intended to convene a combined meeting with the MAP twice a year, and that individual members of the MAP

may be asked for specific advice on other occasions, e.g. in the preparation of a Policy Statement or publication programme. I do not know whether this schedule of regular meetings was adhered to. I am unable to add any more information over and above what is set out in the documents provided by the Inquiry.

*Q13 How did the answers to the above questions 11(a)-(f) change after the 11 August 1988 letter?*

37. I have not had sight of a letter dated 11 August 1988. I take this question to be reference to the letter dated 8 August 1988, referenced in question 10. I am sorry I cannot recall any more details about the MAP and I therefore do not have the knowledge on which to answer these questions.

*Q14 Did members of the Medical Advisory Panel disagree with each other? If so, on what issues in particular? How did the Haemophilia Society decide whose advice to follow? Please provide as much detail as possible, providing examples (if any) of disagreements and how these were resolved*

38. I am not aware of any disagreements between members of the MAP – any such differences, if they existed, would have been aired in their own discussions at which I was not present (with one exception being the meeting referred to in the Minutes dated 27 April 1990 (document HSOC0010954).

*Q15 To what extent (if any) were the opinions of the members of the Society's Executive Committee informed by the Medical Advisory Panel? What other resources (if any) did committee-members rely on for opinions on the safety of blood products and/or the risks of infection from hepatitis and HIV?*

39. The opinions of the Executive Committee were heavily influenced by the MAP – that was the reason for the existence of the MAP. Other clinicians who were not members of MAP also supplied us with information from time to time.

*Q16 Did the Executive Committee ever disagree with the opinions of the Medical Advisory Panel in relation to the safety of blood products and/or the risks of infection? Please provide as much detail as possible, providing examples (if any) of disagreements and how these were resolved.*

40. The Society did not have the resources (nor any reason) to question the quality of the advice or information received from the acknowledged experts in the field. I am not aware of any occasion when the Society disagreed with the advice of the MAP.

*Q17 To what extent (if any) did the Executive Committee rely on its own judgement when deciding whether or not to formulate policy on the basis of the Medical Advisory Panel's advice? Please provide as much detail in your answer, providing examples (if any) of when the Haemophilia Society did not follow the Medical Advisory Panel's advice particularly in relation to the safety of blood products and/or advice on the risks of infection.*

41. I am not aware of any occasion when the Society failed to follow the advice of the MAP.

**Section 3.2 Hepatitis Task Group**

*Q18 The Inquiry is aware that you were involved in the work of the Hepatitis Task Group [HSOC0003743].To the extent that you have not already answered, please explain what the aims of the Hepatitis Task Group were.*

*a. When was it established? What prompted the Society to set up this task group?*
*b. Who were the members of the Hepatitis Task Group and how were they selected?*
*c. Please explain what the Hepatitis Task Group did during the course of your tenure at the Society*

42. For the reasons already stated I am unable to supply answers to these questions except by referring to the documents supplied to me. As I mention above, I was a member of this group but I have no recollection of the meetings or my involvement in the group, other than that I did not feel comfortable in this group as I did not regard myself as sufficiently knowledgeable on the subject to make a viable contribution. I note from the documents supplied by the Inquiry [document HSOC0003743] that G Barker, N Guy, S Taylor, and S Marshall and myself attended a meeting of the Hepatitis Task Group on 18 July 1994. Graham Barker was the Policy Manager, Simon Taylor was an Executive Committee member with an interest and expertise in policy, Norma Guy was an Executive Committee member and was well connected to represent the interest of local group members, and Shanit Marshall provided administrative and secretarial support to the group. I cannot remember exactly why the Hepatitis Task Group was established, or what it did during the course of my tenure but it clearly reflected a growing concern with hepatitis at the time.

*Q19 What role did the Hepatitis Task Group play in the campaign for compensation for people infected with HCV [HSOC0023353]*

43. I barely remember the existence of this group and I therefore have no means of answering these questions, other than by reference to the documents supplied by the Inquiry. I have reviewed document HSOC0023353 referred to in question 19. I note that this is a meeting minute that contains an update from the Hepatitis Task Group and discusses a proposal for a hepatitis C publicity campaign. However, I cannot recall

anything more than what is recorded in the minute about this group's discussions and I am therefore unable to explain what role this group played in campaigning for compensation for HCV victims.

*Q20 What was the Hepatitis Campaign Group? What (if any) was the relationship between the Hepatitis Task Group and the Hepatitis Campaign Group? [HSOC0026495]*

44. I have no firm recollection of the reasons for the establishment of the two groups, but I think that there was a desire to separate the issue of campaigning from the need to learn about the nature, implications and treatment of Hep C.

*Q21 Please describe the relationship between the Hepatitis Task Group and the Manor House Group [HSOC0023353; HSOC0015306]. What was the purpose and function of the Manor House Group?*

45. As I recall the Manor House Group was a group of individuals (I am not sure whether or not they were all members of the Society) affected by Hepatitis C who were particularly militant in their grievance over their infection and their desire for compensation. As I remember it, they wanted the Society to campaign aggressively, in a high profile way for compensation and were angry that the Society did not act in the ways they advocated. The relationship was strained, as the Society generally took the view that more would be achieved by pursuing a more measured strategy. Looking back at minutes (referred to in the question) from the aftermath of the HIV campaign, the Society recognised that the focus on the HIV campaign had absorbed a huge amount of the Society's limited resources, perhaps at the cost of neglecting other issues. I think the Executive Committee was wary of becoming overcommitted to a single issue, as well as being concerned that it would make life more difficult for people with haemophilia if a Hepatitis C campaign led to press coverage that resulted in all haemophiliacs being disadvantaged and branded as "untouchables" as happened in the early years of the HIV/AIDS publicity.

## Section 4: Communication and Dissemination of Information by the Society

### 4.1 Knowledge of Risk

*Q22 When you first joined the Society:*

*a) What did you know and understand about the risks of the transmission of HBV 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*

*HCV (or Non-A Non-B Hepatitis) 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 HIV/AIDS from blood and blood products by others within the Society? What were the sources of your knowledge? How did your knowledge and understanding develop over time?*

46. It is important for me to state that I cannot separate in my mind what knowledge I had in my personal capacity from what I learned as a Trustee. I had been aware from an early age that blood products carried a risk of liver damage, as my Consultant, Dr S H Davis, had informed my parents of this risk when I was a child (although I cannot recall if the specific risk of hepatitis was raised). However it was around 1970 (when I was around 18 years old) that I became aware that HBV could be transmitted through blood. I was aware that I should take care not to let others touch my blood, for example, if I cut myself. I learnt about the risk of transmission through personal interaction with my Haemophilia Centre, and I was also kept informed about developing knowledge of blood borne infections (including HCV, HVB and HIV) through my involvement as a member of the Society and regularly attending haemophilia centre clinics. It was a constant learning process and I cannot in retrospect identify any occasions or events when my knowledge changed.

*Q23 When the Medical Advisory Panel met on 27 April 1990 [HSOC0010954], it was noted at paragraph 7d that, "A number of people are known to be Hepatitis C positive from blood tested from stored samples. This brought up the old ethical dilemma of how to inform people of a test result that they have not asked for".*

*a. When did the Society become aware that HCV testing was being performed on stored samples?*

*b. What did the Haemophilia Society do in light of this knowledge?*

*c. Why was the Society consulted in regard to this ethical dilemma?*

*d. Did the Haemophilia Society communicate this information to its members? If so, please set out when and provide copies of the relevant publications and or letters. If not, please explain why not.*

47. I am unaware of when the Society became aware that HCV testing was being performed on stored samples, what it did in light of this knowledge, whether the Society was consulted on this matter, or if this information was communicated to the membership. I am only able to rely on the information contained in document HSOC0010954 supplied

by the Inquiry. I note the document referred to simply says the matter was raised at the MAP meeting. However, if the Society was consulted, it may be because MAP may have wanted to know the Society's position on using stored samples. I cannot recall what the Society's position was.

*Q24 In the Minutes of the Executive Committee, on 14 November 1991 [HSOC0010385] under the subheading 'Hepatitis' it is stated that, "...the Team had concluded that hepatitis should not be a major concern for the Society. 80% of people infected with HCV and HBV would show no clinical signs and the treatments available were limited; the understanding of the progression of liver disease could only be established through liver biopsies, now considered unethical. The team felt that the Society was in danger of creating concern and worry where they need not exist. Publicity and high profile coverage would be out of proportion to the threat that actually existed." Please can you answer the following:*

48. The extract of the Minutes referred to relate to an update from the Hepatitis Project Team. I do not recall the matters discussed at this meeting, nor being a part of that Project Team. In addition, based on a review of the Minutes I cannot see that I was involved in this Project Team. I am therefore only able to answer this question from reviewing the documents supplied to me. My belief is that we would be acting on medical advice and that we would be trying to prevent fear and stigma affecting our members.

*a. Had the Haemophilia Society sought and obtained any advice in relation to HCV before this date? If so please set out who that advice was sought from and what advice was obtained. If it was not sought, please explain why not and please set out the basis for the views expressed in the Minutes.*

49. I note that the Minutes say that the Project Team contacted experts in the field and received comprehensive reports on the current thinking. However, I have no direct knowledge of any specific advice the Society obtained in relation to HCV. I did not provide the update referred to in the Minutes and in fact, the Minutes record me as being absent from the meeting. I am therefore unable to add further to what is recorded in the Minutes, nor am I able to explain the basis for the views set out in the Minutes. I do however note that document HSOC0010470 refers to hepatitis being a topic of concern for the MAP in 1992/1993.

*b. Please explain what was meant by "creating concern and worry where they need not exist". Please describe, in as much detail as you are able and by using appropriate examples, how this conclusion influenced (if at all) the Haemophilia Society's editorial decisions.*

50. I was not present at that meeting. I am therefore unable to explain what was meant by "*creating concern and worry where they need not exist*". However, having read the Minutes, my understanding of that statement is that, having received expert advice, the

Project Team genuinely wanted to avoid creating fear and alarm when experts had deemed that to be unjustified. The Society's experience after the initial AIDS crisis was that many people with haemophilia and their families were stigmatised and victimised because of misinformed public prejudice. The Society would have wanted to avoid a repetition of that scenario, and this would have likely been taken into account in the editorial decisions.

*c. How and on what basis did the Project Team and/or the Haemophilia Society conclude that "[publicity and high profile coverage would be out of proportion to the threat that actually existed"? Why was the Haemophilia Society concerned about the publicity and media coverage of a Hepatitis C Campaign? [You may also be assisted by HSOC0023353]*

51. For the reasons set out above I am also unable to confirm why the Society concluded at that meeting that "*publicity and high profile coverage would be out of proportion to the threat that actually existed".* However, I believe that it is likely that conclusion would have been reached on the basis of the expert advice received at the time as to the threat posed. In relation to the second half of question 24(c), I have reviewed document HSOC0023353 which are minutes of a meeting dated 10 November 1994 which refer to the possibility of a high profile hepatitis C publicity campaign. I do not recall this meeting, but after reviewing document HSOC0023353, I am aware that I expressed the view that such a publicity campaign would cause damage to the Haemophilia community and outweigh any gains. I believe my reason for that comment is that I think the Society, at that time, would have been concerned about publicity and media coverage endangering the relationship between the Society, the medical profession, the government and the Macfarlane Trust. The Society had worked hard and with some success, to bring about the establishment of the Macfarlane Trust, and saw a similar approach as being most likely to succeed in respect of Hepatitis C infection. The Society would have also been careful to balance the need to provide information to the public, but also not induce panic. The HIV crisis had led to children being shunned, individuals suffering public abuse and discrimination, and the Society would have wanted to avoid similar consequences for affected individuals that might have arisen from a high profile hepatitis C campaign.

*Q25 The Bulletin No.1 – 1994 opened with an article called "Hepatitis C - A Cause For Concern" [RFLT0000071]. What prompted the Society to change its position following the Executive Committee Meeting on 14 November 1991 referred to in question 24?*

52. I believe the Society would have changed its position between 1991 and 1994 due to the advancing state of medical knowledge communicated to the Society. I also note that document HSOC0003743 refers to notes of a 'Hepatitis Task Group' meeting on 18 July 1994, which describes the work carried out by the Task Group on behalf of the Society to explore various issues relating to HCV. The output of this group may well have contributed to the Society's position on HCV. Publication of the article would have been

motivated by our commitment to keep the membership up to date with the best information available at any given time.

*Q26 Prior to Bulletin No. 1 - 1994 being published [RFLT0000071], what information and advice did the Haemophilia Society provide to members on the:*

*a. Risk of Non-A Non-B Hepatitis/ HCV 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 Non-A Non-B Hepatitis/ HCV infection during the relevant period? Please detail the method of communication and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how; and*

*c. prevalence of Non-A Non-B Hepatitis/ HCV infection amongst haemophiliacs during the relevant period? Please detail the method of communication and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how*

53. I cannot recall what information the Society provided to members on HCV, except to say that the Society acted on the best medical information available to us at any time. I note that document HSOC0003743 details some of the actions that were intended to be taken to provide information to people with haemophilia and their families, and these actions included a Bulletin Q&A to be included in the October 1994 issue, updating the booklet on hepatitis, liaising with HCDO, liver specialists and the British Liver Trust to obtain information on the symptoms and progression of HCV. In addition, one of the action points for the Hepatitis Task Group was to gather more information on the prevalence of HCV infection, However, as I have described above, I cannot recall information about my involvement in the Task Group and I am therefore unable to add anything further to the information contained in the documents supplied by the Inquiry.

*Q27 When and in what circumstances did the Haemophilia Society become aware of any risks of transmission of vCJD associated with the use of blood and blood products? What were the sources of their knowledge? How did their knowledge and understanding develop over time?*

*Q28 What actions did the Haemophilia Society take in relation to the risk of transmission of vCJD via blood products? What representations (if any) were made to Haemophilia Society members, the Government or the UKHCDO in relation to these risks?*

54. In relation to questions 27 and 28, I cannot recall any information relating to the circumstances in which the Society became aware of the risk of vCJD infection, nor the

actions taken in relation to the risk of transmission of vCJD. In my personal capacity I received information about vCJD from the Haemophilia Centre in September 2004, after I had ceased to be actively involved with the Society.

**4.2 Communication and Policies on Imported Blood Products**

*Q29 Please identify the Haemophilia Society's bodies, committees or task groups that were responsible for advising the Haemophilia Society on the safety of blood products.*

55. As I have described above, I cannot recall details of the various Society groups and committees and I am unable to recall what specific bodies, committees and task groups that would have been involved on the safety of blood products. It is only from the documentation the Inquiry has supplied to me that I can identify any groups that worked on these matters. I note that document HSOC0010398 refers to a blood products policy that had been evolved by a Project Team consisting of myself, Mr Milne and the General Secretary. I have no recollection of this Project Team, however it is highly likely that MAP and Centre Directors would have been consulted on the development of any blood products policy.

*Q30 Please detail how the Haemophilia Society's advice on the safety of imported blood products developed during your tenure. What information did the Haemophilia Society communicate to members? How did this information change over time?*

56. I cannot recall the details of specific information issued, but the Society would have shared the best advice available to us from Centre Directors or members of the Medical Advisory Panel. The information we provided would have changed in line with the advice we received.

*Q31 To the best of your knowledge, what resources did the Haemophilia Society rely on to evaluate or advise on the safety of imported blood products? In your answer, please provide details regarding the involvement of medical professionals in the decisions and policies formulated by the Haemophilia Society.*

57. The Society could only rely on information we received from the medical experts who supplied us with information – either in the form of articles for publication or in informal conversations. The Society was not, and was never intended to be, a medical or scientific institution able to carry out its own research. It was a vehicle for communicating to members the general advice available from the medical profession. Generally, this would be from the Medical Advisory Panel although other clinicians or Centre Directors may have given input from time to time.

*Q32 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 how frequent these communications were. [BPLL0002037 may assist you.]*

58. I cannot recall any information about the extent to which the Society relied on communications from pharmaceutical reps about the safety of blood products. They would be one source of information, but evaluation of that information would be the domain of our medical advisors. Any contact I had with reps from pharmaceutical companies was at conferences they attended or sponsored and, as far as I can remember, were purely social interactions.

*Q33 Please detail the role of the Haemophilia Society in commenting, drafting or advising on Haemophilia Centre Directors' Organisation (HCDO) guidelines on recommended products. [You may be assisted by HSOC0029689_006 and HSOC0019923_038].*

59. I note document HSOC0029689_006 says the Blood Products Task Group would comment on the HCDO draft guidelines. I cannot remember whether I was a member of this group. It may be the same Project Team mentioned in document HSOC0010398 referred to at Q.29. I am unable to add anything further to this as I do not recall any information about the Society's involvement in commenting on or drafting the guidelines. However, I do not think it would have been usual practice for the Society to comment on HCDO documents, as the Society would recognise the HCDO as being authoritative.

*Q34 To the best of your knowledge, did the Haemophilia Society disagree with HCDO guidelines on recommended products in relation to the safety blood products? If so, please provide details of these disagreements (if any) and how these were resolved.*

60. I do not remember any such disagreement.

*Q35 On 7 October 1990, the Haemophilia Society's Policy Committee agreed on the "Blood Products Policy" that "upholds the principle of a voluntary donor based system within the United Kingdom adequate to ensure self-sufficiency [....] The Society acknowledges that until this goal is achieved it remains necessary to use certain imported products from paid donor sources" [HSOC0010398]. How did the Haemophilia Society agree on this policy? Why did the Haemophilia Society consider it necessary to continue the use of imported blood products? Did the Haemophilia Society approve of specific "imported products from paid donor sources"? If so, which ones? [You may also be assisted by HSOC0017203]*

61. I cannot remember the process by which the Society agreed on this policy, but to the best of my understanding it was an "article of faith" among the haemophilia community

that a system of voluntary blood donation is the best. Given that the UK domestic supply could not meet the demand, it was regarded as a necessary evil that imported commercial product would be used. Only someone who has suffered the excruciating pain of an acute haemophilic bleed in a joint can appreciate the overwhelming need to treat that bleed as quickly and effectively as possible. However, I am not aware of the Society approving or disapproving of specific products. The Society had no power to make decisions about such matters.

**4.3 Publications**

*Q36 Please identify the members, groups and/or committees of the Haemophilia Society responsible for editing and selecting material for the Bulletin, Haemofact and other Haemophilia Society publications during your tenure. In your answer, please detail your role as "Editor of the Bulletin" and the extent of your involvement with other Haemophilia Society's publications.*

62. I have addressed my role as publications editor in response to Q.6, above. To the best of my recollection, when I became publications editor I worked with David Watters in the production of the Society's publications. These included the Bulletin, Updates, Group Seminar Proceedings, C Issues and Haemofacts. Further information about these publications is set out in my response to Q37, but my main involvement was with the Bulletin as this was our flagship quarterly publication and the other titles were occasional. I do not ever remember a formal "editorial Committee" meeting although I could not swear that such meetings were not held.

63. David worked in the Society's offices in London and I from my home in Scotland. Occasionally we might have discussed the Bulletin when I was attending meetings in London. Those visits would be filled with discussions on a range of topics and some would probably have focussed on publications. Most of our discussions would have been by telephone and as I have explained, I had a fax machine supplied by the Society to facilitate the exchange of hard copy.

64. I relied on David to source most of the material as he was better connected with any possible contributors. He and I would make suggestions about topics or authors we might approach – although I am unable now to give any concrete examples of that. It was an ongoing process. I do not remember much about the production process before we employed a professional publishing firm in the production. The company I think was called Health Network (I found a reference to that name in the documents supplied). I remember dealing with Mark Weaving (one of two brothers who owned the company). We occasionally met at the Society offices to discuss publications along with David Watters.

65. Apart from trying to ensure a balance in the content of the Bulletin (see my response to Q6), much of my input was in adjusting layouts and proof reading – in particular picking up on any grammatical or spelling errors. The Chairman, Rev Alan Tanner always reviewed a final draft of the Bulletin and I do remember at one point he insisted that his name appeared as a member of the "Editorial Board" because for some reason over time it had been omitted from that page of the Bulletin.

*Q37 To the best of your knowledge, please detail the publications that the Haemophilia Society sent out to its membership from 1986 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*

66. The Bulletin was published quarterly and was the flagship publication, covering medical topics, local group news, fundraising efforts etc.

*b) Updates*

67. I think these began life much later than the Bulletin and were designed to be published "mid-term" in relation to the Bulletin

*c) Group Seminar Proceedings*

68. I had forgotten about Group Seminar Proceedings until I received this Rule 9 request but they were an attempt to share the information given at Seminars for the benefit of those unable to attend. They were occasional publications – perhaps appearing annually reflecting recent Group Seminars. I think they tailed off as the substance of group seminars would be reported in the Bulletin. Having read some past copies of the Bulletin, I note that over time the Group Seminars changed their title to Haemophilia Days and Chairman's Weekends.

*d) Haemofact*

69. This occasional series was started (before my time a trustee and editor) to provide an immediate source of information to members as the HIV crisis came to light. The production process was simple as the priority was speed, not design input. They were designed to be written quickly and I am not sure if I would reviewed every one, there would have been limited production input required from me.

*e) C Issues*

70. I had forgotten about this series until the Inquiry reminded me of it. I think the intent and production values were similar to those of Haemofacts, but obviously with the emphasis on Hep C.

71. I am unable to recall details of any other publications, although there may well have been other forms of publications during my tenure. I think in the beginning Updates and the Haemofact series were written by members of the Executive Committee, no doubt using sources supplied by medical experts (likely being MAP, Centre Directors and other clinicians the Society developed contacts with), but I cannot recall any more information about members, groups and/or Committees that were involved in these publications.

72. I believe all publications were distributed to all members of the Society.

*Q38 To what extent, if any, did haemophilia centre directors and members of the Medical Advisory Panel assist in proposing and/or editing and/or selecting material for the Haemophilia Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).*

73. I don't remember any centre director or member of the MAP proposing articles, although that could have happened in their contact with David Watters. We would approach them with a request for an article. I am not aware of any of them editing or selecting articles for publication, other than in respect of their own articles, which would have been done before they reached me. As described above, as far as the quarterly Bulletin is concerned, I would have discussions with David Watters about what was current in the world of haemophilia, and we would agree who should be approached to write articles for publication. This would generally have been members of MAP, Centre Directors and other relevant clinicians the Society had links with.

74. I have also mentioned in my response to Q11-17 that members of MAP contributed articles to the Bulletin and Update and I presume these were in response to requests made by Executive Committee members or by David Watters. I would not have personally been involved in liaising with MAP. David and I would have discussed what content to include in the Bulletin and who to approach, and David would have liaised with the appropriate individuals.

*Q39 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? If you have already answered this question in other sections of your response, please identify the paragraph number(s)*

75. In general, I am not aware of any pharmaceutical company representatives playing any active role in the content or presentation of our publications. They sponsored the

publication but did not influence its content. The only article that might be an exception to that general rule is the Update dated April 1989 (document HCDO0000276_018). This featured Alpha Therapeutic UK Ltd under the headline "ALPHA a decade of service to haemophilia". I have no knowledge of how it came to be featured, but it is reasonable to presume that it was initiated by the company.

### 4.3.1 The Bulletin

*Q40 Was the Bulletin distributed, or otherwise made available, to healthcare professionals by the Haemophilia Society? What was the Haemophilia Society's understanding of the extent of its reach amongst those who provided medical care and treatment to haemophiliacs?*

76. I never saw the mailing list for our publications, but I presume centre directors and other health care professional were supplied with a copy. Our aim was to disseminate our publications as widely as possible. I presume Haemophilia Centres would receive multiple copies for display as copies were usually on display when I visited the Edinburgh centre and other Reference Centres. It was always my impression (from comments received at conferences etc) that the Bulletin was warmly regarded by doctors. This was part of our rationale for trying to include a "heavyweight" medical or scientific article in each edition - to lend the Bulletin credibility with the professional audience.

*Q41 How did the Haemophilia Society select or identify contributors and interview subjects for the Bulletin? Specifically, in relation to Bulletin articles which gave medical and/or other opinions about the safety of blood products and the risk of infection, how were the contributors for these articles selected?*

77. I can add little to my previous answers referring to personal contacts and, in particular, those made by David Watters and my responses to Q6 and Q36 above. From a review of the documents supplied by the Inquiry, I note that members of MAP sometimes wrote articles for the Bulletin (for example the Minutes of the Executive Committee, dated 4-5 October 1991 [HSOC0010387] notes that Dr Mayne was going to write an article on high purity products)

*Q42 To what extent (if any) did the Haemophilia Society verify medical and scientific information and/or opinions provided by contributors to the Bulletin? If verification took place, please describe the process by which this occurred.*

78. As already mentioned, until Dr Evans joined the Executive Committee in 1993 no one on the Executive Committee was a medical expert and we were reliant on information supplied from medical professionals. That was the very reason for having a Medical Advisory Panel. They were leading national experts and so it was not necessary to check what they were saying. Even if we had the funds to instruct independent experts to

crosscheck, we would have gone back to the same group. As already stated, the Society was not learned medical or scientific body, and had neither the expertise not the resources to question or verify expert medical opinion. As neither The Bulletin nor the Haemofact series was a refereed or scientific journal it was beyond the scope of the Society to try to validate or verify information contributed by recognised experts.

*Q43 In a "Note For Contributors to the Bulletin and Update", dated January 1990, you state that the Society reserves the "right to amend, edit or reject any article submitted for publication". Did the Haemophilia Society exercise this right in relation to articles on medical and/or other opinions about the safety of blood products and the risk of infection? If so, please provide details on the proposed publications and the basis of decisions not to publish and/or amend.*

79. I am not aware of any occasion when we had to exercise that reserved right.

*Q44 In the Minutes of the Executive Committee, dated 4-5 October 1991, you are reported as saying "that The Bulletin was a forum for debate and should take into account all the medical evidence on a range of issues" [HSOC0010387]. Please can you elaborate. How did the Haemophilia Society identify issues of "debate"? How did the Haemophilia Society ensure that "all medical evidence" was being accounted for in its articles on a specific issue?*

80. I have reviewed document HSOC0010387 and I cannot specifically recall this meeting and cannot add anything to the statements recorded in the minute referred to. In describing the Bulletin as a forum from debate, I was probably alluding, rather obliquely, to the fact that the Bulletin was not a learned academic journal. It was communicating the best information we had available from range of contributors, including MAP, Centre Directors and other clinicians the Society had links with. My words about being a forum of debate probably related to a general principle rather than a specific issue. Also I think I hoped we could generate correspondence via a "letters to the Editor" section. I have recently been able to read the Bulletin 1991, Issue 4, published in November 1991 (WITN3647004) in which I have written a piece explaining the Society's position on the Bulletin being a "forum for debate" and defending the Bulletin's editorial independence from its commercial sponsors. The article explains that "*the views expressed are not necessarily those of the Society … We are eager to encourage the use of the Bulletin as a forum for debate, and, in this issue we are happy to publish comments received in response to the articles in question*" (WITN3647004).

*Q45 Did the Haemophilia 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 Haemophilia 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.*

81. I have no knowledge of Haemophilia Clinicians who felt their views on imported blood products were not being represented. The Society would have been reliant the views of medical professionals at the time. As far as I can recall, there was no disagreement in the medical profession as to use of imported blood products.

*Q46 In the Minutes of the Executive Committee, dated 4-5 October 1991, David Watters "reported on a controversy that had arisen over the publication of three articles on monoclonal or high purity products in the recent issue of the Bulletin [Bulletin 1991 Issue No.3]. Having read them, a few Society members had approached their Centre*

*Directors with requests for the products and this had caused a certain amount of consternation" [**HSOC0010387**]. Please can you detail how these articles came to be published in the Bulletin and the "controversy" that had arisen.*

*a) Why were Centre Directors concerned by members requesting monoclonal or high purity products?*

82. I can add nothing to what is recorded in the minute.

*b) What prompted the Haemophilia Society to publish the articles on high purity products?*

83. The articles would have been sourced in the usual way, in discussion between David Watters and me in pursuit of the most up to date knowledge because it was a relevant issue for membership. Purity of products was high on our agenda and awareness, and if we had become aware through contacts and clinicians that new products were on the way we would have tried to obtain the best information we could and share it with our membership.

*c) How did the Haemophilia Society select and/or identify the "three American haemophilia experts" (that contributed to the article "Product Purity") and contributions by* GRO-D *("who authored the article on "letters from America")? [**HSOC0022976**]*

84. I have no recollection of how this took place.

*d) It is also stated that "Dr Elizabeth Mayne had agreed to write an article for the next issue on some of the problems related to the use of high purity products, thereby presenting the other side of the argument". How did the Executive Committee come to understand that there were differing opinions on the use of high purity products?*

*Did the Haemophilia Society seek opinions from the Medical Advisory Panel and/or medical advisors on the subject of high purity products prior to publication?*

85. I have no way of knowing after all this time.

*e) In the minutes, "the Chairman remarked that the Society might be perceived in certain quarters to be favouring a particular pharmaceutical company, and that such sensitivities ought to be borne in mind in the future" [**HSOC0010387**]. Please can you comment. What pharmaceutical company was the Society perceived as favouring in these articles? Did this result in a change in what was published by the Society? If so, what was that change?*

86. I think this might refer to the ALPHA article discussed in answer to Question 39, but if it does not I have no idea what provoked the comment.

### 4.3.2 Haemofact

*Q47 Please identify the members and/or committees of the Haemophilia Society responsible for editing and selecting material for the Haemofact.*

87. As stated in response to Q36 the Haemofact series began publication before I was involved and I think that initially it was written by members of the Executive Committee, no doubt using sources supplied by medical experts. With no evidence to support my guess, I think Clive Knight and Ken Milne (both now deceased) may have written earlier editions and Simon Taylor may have had a hand in later issues. I have attached at WITN3647005 Christopher Ludlam's evidence to the Penrose Inquiry which gives a fairly detailed list of Haemofacts and their authors.

*Q48 Please describe how the Haemofact was made available to healthcare professionals. What was the Haemophilia Society's knowledge of the extent of its reach amongst professionals who provided medical care and treatment to haemophiliacs?*

88. As with other publications I believe Haemofact would have been circulated to our entire mailing list with multiple copies sent to haemophilia centres.

*Q49 In 1990 Professor Bloom prepared a report for the 1991 HIV Litigation [**BPLL0001351_076**]. At page 174, he notes that: "From May 1983 the Haemophilia Society circulated their members and Haemophilia Centres with a series of pamphlets on AIDS called 'Haemofact' which contained relevant information and advice. These pamphlets were produced by the Society but not with input from the Medical Advisory Panel. I have no firm knowledge of the source of the factual information needed to prepare the pamphlets…". Please comment on the accuracy of Professor Bloom's*

*statement. To what extent (if any) did the Haemophilia Society rely on its medical advisors and/or the Medical Advisory Panel for the content of Haemofact? What other resources (if any) did the Haemophilia Society rely on?*

89. I disagree strongly with Professor Bloom's statement that Haemofact pamphlets were produced without the input of MAP. I believe that statement to be untrue. I note that Christopher Ludlam's evidence to the Penrose Inquiry at WITN3647005 states that authors of Heamofacts included members of MAP (including Professor Bloom). The Society relied heavily on members of the MAP and other doctors as sources of information, along with other centre directors and possibly World Federation of Haemophilia publications. As already stated, members of the Executive committee were not doctors (until Dr Evans joined in 1990) so could only rely on information supplied by members of the medical profession.

**4.3.3 Other communications**

*Q50 Did the Haemophilia Society receive direct inquiries from the public or members who required advice with regard to the safety of blood products? If so, how were these queries handled? Who would respond? What resources (if any) did the Haemophilia Society rely on to enable a response? Please set out specifically, to the best of your knowledge, what advice and/or information the Society had and from whom that had been provided.*

90. I am sure the Society would receive direct enquiries about the safety of blood products, but I would not have dealt with these enquiries. These would have been dealt with by the staff in London. I was living in Scotland and I never personally received any such enquiries so I do not know how these would have been handled. However, I do not imagine that the Society would have given direct advice, individuals would have most likely been told to approach their Centre Directors. However, it is possible that information about available products may have been provided.

*Q51 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.*

91. I do not know what Chris James meant by the use of the word "spearheaded". As already explained, the Society is not a medical or scientific organisation. The information it disseminated could only come from the medical and scientific community. I believe that the information the Society published was, in general, solicited by the Society from its

medical advisors. I am not aware during my tenure that the doctors took the initiative in supplying articles or documents.

*Q52 With regard to Group Seminar Proceedings [for example **PRSE0003316** and **PRSE0003074**]:*

*a. How, and by whom, was it decided that a Group Seminar should be held?*

92. The two documents cited in the question 52 regarding the Group Seminar Proceedings were published in 1981 and 1983, before my active involvement in the Executive Committee, so I can only apply hindsight to answer in respect of these publications. I was not involved in organising Group Seminar Proceedings but I would have attended them and played an active part, and may have written up a report on the seminar afterwards. I cannot recall the detail of the seminars but they would take place two or three times a year and provide an opportunity to get together, share views and meet other haemophiliacs. I cannot remember whether we continued to use the term Group Seminars after I became a trustee or whether they we given different titles – e.g. Haemophilia Days, the Chairman's Weekend. Whatever the name, the purpose would remain the same.

93. I believe the Executive Committee would make the decision to hold these events to allow as many members of the Society as possible to hear first-hand the latest and best information about the condition and its treatment. Group events also provided a forum for mutual support within the membership. One of the problems with haemophilia (and related conditions) is their rarity and therefore the geographical dispersion of people with haemophilia is a real problem in making support available to all members. The Group Seminars and the subsequent publication of the meetings was a means of involving and informing the membership.

*b. How, and by whom, were Group Seminar topics decided?*

94. I cannot recall how Group Seminar topics were decided or speakers selected but Imagine the topics would be selected by the Executive Committee or a sub group thereof, using contacts on the MAP or other approachable doctors.

*c. How were speakers selected to speak at a Group Seminar?*

95. I cannot recall precisely how speakers were selected. There would have been input from David Watters and the Exec Committee, and the Chairman would have had final sign off.

*d. What was the purpose of publishing the Proceedings?*

96. The Group Seminars and the subsequent publication of the meetings was a means of involving and informing the membership, offering members the chance to meet, and enjoy fellowship with those in a similar situation to themselves.

*e. To whom, and how, were the Proceedings disseminated?*

97. From the documents supplied to me by the Inquiry it is clear that the proceedings were published in the Bulletin and distributed through the Society's mailing list.

*Q53 Please detail any other activities that the Haemophilia Society conducted with the purpose of disseminating information to its members during your tenure. If this changed over time please detail when and why.*

98. The publications cited in these answers, group seminars and AGM speakers and Annual Reports were the only means of dissemination I can remember.

**4.3.4 Communication to and with Healthcare Professionals**

*Q54 Please detail any other activities the Haemophilia Society conducted with the purpose of disseminating information to healthcare professionals during your tenure. If this changed over time please detail when and why.*

99. I am not aware of any activities directly aimed at healthcare professionals, save that we sought to make our publications available to Haemophilia Centres. The Society welcomed the presence of special interest groups e.g. the Haemophilia Nurses Association, but these were entirely independent entities.

*Q55 In a memo entitled, "Medical Advisory Panel" authored by the Haemophilia Society's Project Team, dated April 1991, it is stated that, "Society's lobbying might be more effective if endorsed by a Medical Advisory Panel. Politicians, civil servants, health professionals, staff in smaller Centres and some patients might fall into this category" [underlining added] [HSOC0010277]. To the best of your knowledge, did the Haemophilia Society lobby health professionals and/or staff in smaller centres during your tenure at the Society? If so, how and for what purpose?*

100. I am not aware of the Society lobbying any centres. The Society attempted to disseminate best practice for haemophilia centres though its publications in order to make the publications available to families and patients who attended the centres. However, I cannot recall anything that could be described as lobbying activity. Local group members may have asked their centres about treatments or facilities, but this would not amount to lobbying by the Society. My understanding of this memo is that the lobbying refers to lobbying the government or health authorities and not individual centres.

## Section 5: Relationship with Pharmaceutical Companies

### 5.1 Financial Relationships

*Q56 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.*

101. The Society did rely heavily and gratefully on sponsorship from pharmaceutical companies. I cannot recall the details, but to my knowledge, such sponsorship funded many of our publications – the source of such funding was always acknowledged. I think that group conferences and Executive strategy weekends were also sponsored, at least in part. I cannot quantify the amounts involved. I am not aware that any staff were appointed using pharmaceutical company sponsorship.

*Q57 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*

102. The financial relationships were dealt with by David Watters. Before his appointment, I imagine members of the Executive Committee would make the contact, but I was not involved in the financial relationships.

*Q58 How, if at all, did the Haemophilia Society's fundraising activities develop over your tenure? What factors or activities, if any, contributed to increasing or decreasing financial contributions to the Haemophilia Society from pharmaceutical companies manufacturing and/or supplying blood products?*

103. I cannot give any quantitative detail of fundraising income, but in general the Society's local groups tried their best to raise funds but there is no doubt that funding from the pharmaceutical companies played a significant part in allowing the Society to expand its activities. The documents I have seen have reminded me that the Society entered into relationships with two professional fundraising agencies but I am not sure that they were particularly successful.

104. I was an active member of the local Scottish group up until at least 1996. At that time, I was involved in a number of different fundraising events, and other activities such as giving talks to local Rotary Clubs and other societies or voluntary bodies. The Bulletin records all sorts of fund raising activities by the local groups of the Society. For example for a time, the Perth Group of the Society ran a charity shop. I still receive Haemophilia Society publications and can see that the same types of fundraising activities are still going on – marathon sponsorship, charity concerts etc.

*Q59. Please explain any differences in the Society's relationships with individual 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?*

105. I had no involvement in negotiating sponsorship with the pharmaceutical companies therefore I am unable to explain the Society's relationship with individual pharmaceutical companies. My involvement with pharmaceutical companies was generally on a social level if I would see reps at meetings or conferences. I can remember meeting a couple of the pharmaceutical company representatives at conferences and one hosted a tour of their facilities in Cambridgeshire. However, I do not recall discussing donations.

*Q60 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?*

106. I believe the return to the companies would have been through the use of their brand names on our publications or their acknowledgement as sponsors of conferences. At conferences, it would be normal practice to have pop-up stands and tables displaying their product information.

*Q61 A number of the Haemophilia Society Bulletins publish which pharmaceutical company funded the production of the Bulletin. Was publishing this information a requirement of their funding? What was agreed in this regard? How was this agreed?*

107. I believe we considered it normal practice to acknowledge sponsorship as part of a transparent business relationship. However, I am not aware that it was ever necessary to deem it as a "requirement" before sponsorship was agreed.

*Q62 Please comment on the article, "Alpha Therapeutics UK Ltd - A Decade of Service to Haemophilia", published in Update No.3 June 1989 [HCDO0000276_018, page 5]. Who wrote this article? To what extent did Alpha rely (if at all) on this publication disseminated by the Haemophilia Society to promote their products or their public image?*

108. I am unable to add anything further to the contents of the Alpha article HCDO0000276_018, page 5. I do not know who wrote the article, how it came to be in our in-tray or the extent to which Alpha relied on this publication, or any other, to promote its products. I may have been involved in the publishing of this article but I cannot recall any details about it and I would refer to my response to Q39.

*Q63 Did the Haemophilia Society publish or disseminate any articles or publications in exchange or with the expectation of receiving financial contributions, or any other benefit, by pharmaceutical companies? If so, please provide details on the nature of these articles or publications.*

109. See my response below.

*Q64 Did the Haemophilia Society refrain from publishing or disseminating any articles or publications in exchange or with the expectation of receiving financial contributions, or any other benefits, from pharmaceutical companies? If so, please provide details on the nature of these articles or publications.*

110. In relation to questions 63 and 64, I am not aware that the Society published (or refrained from publishing) any articles for reasons of financial contributions/benefits by pharmaceutical companies. I think it would be quite against our principles to conduct our affairs on these terms.

**5.2 Other Relationships**

*Q65 Did the Haemophilia Society rely on pharmaceutical companies for assistance or support, other than financial contributions? If so, please provide as much detail as possible on the support provided, the specific activities/functions that pharmaceutical companies supported, and the names of pharmaceutical companies involved.*

111. As far as I am aware pharmaceutical companies gave support by sponsoring publications, conferences and delegates' attendance at international meetings. Such sponsorship was acknowledged in the appropriate publications or reports. However, I cannot recall details of the specific activities sponsored or the companies involved. As already stated, I was not involved in negotiations with pharmaceutical companies.

*Q66 What relationship (if any) did the Executive Committee-members of the Haemophilia Society have with pharmaceutical companies?*

112. The pharmaceutical reps attended our conferences in the UK and internationally at WFH and there was normal social interaction at these meetings. The pharmaceutical

companies would host dinners during WFH meetings to which Society representative were sometimes invited. I did attend some of these dinners. I think most members of the Executive Committee would have known the reps from the major pharmaceutical companies, but to my knowledge there would be no direct business relationship. David Watters was not a member of the Executive Committee, but in his role as General Secretary, he would have managed sponsorship matters on behalf of the Executive Committee with the companies.

*Q67 To the best of your knowledge, did any representatives of pharmaceutical companies join the Haemophilia Society, either while they still worked for the pharmaceutical company or after they left?*

113. I do not know with any certainty if any pharmaceutical representatives became members of the Society – I have a vague memory that one or two might have joined as individuals but cannot recall any information about them.

*Q68 To what extent, did the Haemophilia Society, through its activities and functions, attempt (if at all) to assist pharmaceutical companies to promote their products and/or public image? If so, please provide details, specifying the pharmaceutical companies, the products, the Haemophilia Society's activities and functions, and the way in which these activities and functions promoted the pharmaceutical companies products and/or public image.*

114. I am not aware of the Society promoting any particular company or product over any other, however as described above, pharmaceutical companies would be acknowledged if they had sponsored articles or conferences. I cannot recall any rules or protocols which limited or prevented the Society from endorsing pharmaceutical companies, but I believe there was a common understanding among the Executive Committee that this would not be done.

**Section 6: Relationship with the Government**

*Q69 Please identify the extent of your role and involvement with regard to the Society's representations to the Government.*

*Q70 Please detail the Haemophilia Society's relationships with the Government and individuals in public office. Who were the main points of contact? How were these relationships formed?*

115. In relation to questions 69 and 70, I have addressed this in response to Q7 above. After hearing evidence from David Watters, I now recall that the Society had a relationship with GJW Government Relations, although I did not attend meetings with GJW and do not

know the detail of the relationship. I had very little involvement with respect to representations to Government and cannot recall details about the Society's involvement with Government. I remember attending one meeting at the Department of Health, but I cannot remember who participated in the meeting, the date or the substance of the meeting. As stated previously, being based in Scotland, and having full time employment I was not readily available to attend meetings in London.

116. I have reviewed document HSOC0010387 and I acknowledge that as part of my involvement on the Policy Committee I provided the Executive committee with an update on parliamentary relations. However, I believe I would have simply been reporting what was discussed at the Policy Committee, as I do not recall any significant personal involvement in government relations meetings. I am aware from the hearing with David Watters that in 1990 a letter was sent out in my name to William Waldegrave, the Secretary of State for Health (1990-92), but cannot recall any details about this. A copy of this letter is at WITN3647006. I note that the copy shown to the Inquiry did not appear to have my signature on it although it was written in my name. The letter may simply have gone out under my signature for some reason I cannot now remember. I am therefore unable to provide any further information on the Society's relations with government.

**6.1 Self-Sufficiency**

*Q71 Please identify who was responsible for determining the Society's position in relation to self-sufficiency.*

117. As with any board or committee, The Executive Committee would have had collective responsibility for determining the Society's position. Sub-committees such as the Blood Products Sub-committee might have collected information from medical experts (such as MAP and centre Directors) with the help of the professional staff and presented their reports to the whole group.

*Q72 To the best of your knowledge, did the Government provide any assurances to the Society on its ability and aim to achieve self-sufficiency during your tenure? If so:*

*a. Please provide details, identifying assurances that the Society received, when they were received and by whom they were given.*
*b. Did the Government place any caveats on these assurances?*
*c. Did the Haemophilia Society rely on these assurances and if so how?*
*d. Were any actions taken by the Society to verify the assurances?*
*e. Were these assurances communicated to members? If so, how?*

118. I am not aware of any assurances the Government provided to the Society regarding self-sufficiency and I am therefore unable to answer question 72.

**6.2 Supply of Imported Blood Products**

*Q73 Please identify who was responsible for deciding the Society's positions and representations made to the Government regarding the use and supply of imported blood products.*

119. The Executive Committee would have collective responsibility for determining the Society's position and representations made to government regarding imported blood products. As I remember it, the Chairman took the lead on decisions in relation to making representations to Government or requesting meetings with senior officials or ministers. The Chairman, Reverend Prebendary Alan Tanner, was very formal and correct in these matters and he definitely saw it as his role to represent the Society at senior levels. As in every other matter, the Executive Committee could only take its position based on information and evidence from its medical advisors.

*Q74 Please identify the goals and priorities, during your tenure, of the Haemophilia Society with regards to the supply of imported blood products. What were the key issues that the Society pursued and during what period?*

120. As far as I can remember, the Society would have regarded self-sufficiency as the gold standard, but it would acknowledge the necessity to use imported product. This is addressed further in my response to question 35.

*Q75 Did the Haemophilia Society receive assurances by the Government or individuals in public office on the use and supply of imported blood products? If so, please provide details of the assurances that the Society received, with details of the individual or department that made them.*

121. I am not personally aware of the Society having received such assurances from the Government on the supply of imported blood.

**6.3 Reduction of Risk of Blood Products**

*Q76 Please identify who was responsible for determining the Society's position in regard to reducing the risk of blood products during your tenure, including by campaigning for recombinant products?*

122. The Executive Committee would have had collective responsibility for determining the Society's position regarding the risk of blood products. I am unable to remember anything that I can add to the contents of the minutes of the Executive Committee dated 7 October

1990 (document HSOC0010398). However, I do think that the Society would have wanted to maintain a balance between keeping its membership informed on the one hand, and creating panic and potentially impeding access to treatment on the other hand. This is addressed further in my response to Q24(c).

*Q77 Please identify the goals and priorities, during your tenure, of the Haemophilia Society with regards to reducing the risk of blood products. What were the key issues that the Society pursued and during what period?*

123. The Society advocated for the use of the safest possible products.

*Q78 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.*

124. I am not aware if any assurances were given by the Government in response to the Society's position on blood products.

**6.4 Campaign for Compensation for HIV/AIDS**

*Q79 What prompted the Society to begin campaigning for recompense for haemophiliacs infected with HIV/AIDS as a result of contaminated blood products?*

125. The desire to correct the tragic injustice of an iatrogenic infection prompted the Society to begin campaigning for recompense for haemophiliacs infected with HIV/AIDS as a result of contaminated blood products. However, there was significant concern around HIV/AIDS and this had led to affected individuals suffering abuse and social isolation due to the level of publicity. The Society was therefore concerned to protect haemophiliacs from abuse and this would have factored in to the way in which the Society campaigned. The Chairman's preferred style was to work behind the scenes in a more low-key way using existing contacts to build up the campaign (such as MPs and other people of influence), rather than engage in a very public high-profile campaign.

*a. When did the Haemophilia Society begin campaigning for compensation for HIV?*

126. I cannot remember when the Society began campaign for HIV compensation. At some point, the Society acknowledged that recompense was more achievable than compensation, but I cannot recall when this was. The understanding within the Society was that the government would not pay "compensation" as legally that would imply guilt or negligence, whereas recompense would be an *ex gratia* means of acknowledging hardship. I refer also to my answer to Q80.

*b. Please outline your role in relation to the campaign for compensation for HIV.*

127. I had not much of a role in the campaign for HIV compensation. Based in Scotland, I was unable to attend many of the meetings that took place in London. I remember facilitating a meeting between David Watters, Dr Peter Jones and a Scottish advocate that took place in Parliament House in Edinburgh, but I was not present at the meeting itself. I cannot remember the advocate's name. Dr Jones was a member of the MAP and assisted the Society in the campaign. They were cooperating on some aspect of the campaign that required an urgent meeting with a Scottish advocate, but I cannot recall the details of this.

*c. To the extent that you have not already answered this above, please identify who was responsible for determining the Society's position in relation to campaigning for compensation.*

128. The Executive Committee would have collective responsibility for the Society's position, but the campaigning was spearheaded by the Chairman (Rev Alan Tanner) and David Watters.

*Q80 What were the goals and priorities of the campaign for compensation for HIV?*

*a. How were the goals set?*
*b. To what extent did the Haemophilia Society achieve these goals during your tenure?*

129. The goal in respect of the HIV compensation campaign would have been to achieve fair compensation and acceptance of the wrong that had been done to infected people, and the Executive Committee would have had collective responsibility for determining the Society's goals. I note that the letter from myself to William Waldegrave Secretary of State for Health, at WITN3647006, shows that the Society was encouraging the government to engage in an out of court settlement for HIV compensation, but the Society's position was to not put forward settlement figures as that was a matter for the lawyers on behalf of the Claimants. However, I think the goals were only partially met. The Macfarlane Trust was set up by the UK Government in 1988 to support people with haemophilia who were infected with HIV as a result of contaminated NHS blood products, and their spouses, parents, children and dependants. However, in the words of the Chairman at the time, the creation of the Macfarlane Trust was only "a start" towards proper financial compensation – hence the use of the term "recompense" rather than compensation. Perhaps even worse in the eyes of the membership was the refusal by the government to accept liability for the tragedy.

*Q81 To what extent (if any) was the campaign for compensation informed by the views of Haemophilia Society membership? Did these differ from the views of the Haemophilia Society, as you understood them?*

130. The Society would have been well aware of the views of the membership. I believe the goals were congruent. David Watters has spoken in his evidence to the Inquiry about the number of telephone calls received at the National Office. The local group representatives would also convey to the Executive directly or through David Watters the views of the local membership.

*Q82 What positions 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 to the extent that you have not already answered this above. Please also explain whether these assurances were relied upon and, if so, how?*

131. I was not personally involved in any of the discussions with Government regarding HIV compensation and I cannot recall any information about the assurances made by the Government regarding compensation.

**6.5 Campaign for Compensation for Hepatitis C**

*Q83 What prompted the Society to begin campaigning for compensation for haemophiliacs infected with HCV as a result of contaminated blood products?*

*a. Please outline your role in relation to the campaign for compensation for HCV;*

*b. To the extent that you have not already answered this above, please identify who was responsible for determining the Society's position in relation to campaigning for compensation for HCV.*

132. The desire to correct the tragic injustice of an iatrogenic infection due to the growing scale and severity of the problem.

133. I had not much of a role in this campaign; the Chairman would have had final sign off on the campaign, but I cannot remember who took the lead in discussions. Based in Scotland, I was unable to attend many of the meetings that took place in London.

*Q84 What were the goals and priorities of the campaign for compensation for HCV?*

*a. How were the goals set?*

*b. To what extent did the Haemophilia Society achieve these goals during your tenure?*

134. The Executive Committee would have had collective responsibility for determining the Society's goals in respect of this campaign. The goals were only met partially, as the existence of this Inquiry demonstrates. Many questions have been left unanswered, and it is to be hoped that the findings of this Inquiry will satisfy this need within the infected and affected community.

*Q85 To what extent (if any) was the campaign for compensation informed by the views of Haemophilia Society membership? Did these differ from the views of the Haemophilia Society, as you understood them?*

135. As previously mentioned, the Manor House Group formed a vociferous pressure group whose views were strongly presented to the Society. While there was agreement about the justice of the cause, there were differences of opinion in how to achieve the goal of compensation. I refer to my answer to Q21, which sets out the Society's approach to campaigning and the reasons for this.

*Q86 What positions 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 to the extent that you have not already answered this above. Were these assurances relied upon? If so, how?*

136. I was not personally involved in any of the discussions with Government regarding Hepatitis C compensation and I cannot recall any information about the assurances made by the Government regarding compensation.

**6.6 Reduction of Risk of Blood Products**

137. The questions contained in section 6.6. have been answered in response to section 6.3, as the question is duplicated.

**6.7 The Supply of Imported Blood Products**

*Q90. Please identify who was responsible for deciding the Society's positions and representations made to the Government regarding the use and supply of imported blood products.*

138. The Executive Committee would have had collective responsibility for determining the Society's position on the supply of imported blood products.

*Q91 Please identify the goals and priorities, during your tenure, of the Haemophilia Society with regards to the supply of imported blood products. What were the key issues that the Society pursued and during what period?*

139. This is addressed in my answer to question 35. I believe that the use of imported blood product was regarded initially as a necessary evil because UK supply could not meet demand, but that any imported blood used should be as safe as possible. The Society's position would have been informed by the medical advice available to the Society at that time, and I do not recall disagreements between medical professionals about the use of infected blood products.

*Q92 Did the Haemophilia Society receive assurances by the Government or individuals in public office on the use and supply of imported blood products? If so, please provide details of the assurances that the Society received, with details of the individual or department that made them.*

140. The use of imported blood products is addressed in more detail at section 4.2 However I cannot recall any specific assurances the Society received from the Government on the use of imported blood products.

**Section 7: Other Issues**

*Q93 What was your understanding of the policies within the Haemophilia Society about what documents would be retained and for what period of time? If this changed over time, please set out your understanding of how this changed.*

141. I do not know whether or not we had a document retention policy. I do not think it was ever discussed. I am unable to provide any further information on this point.

*Q94 To the best of your knowledge, at any point, did Haemophilia Society staff and/or committee-members destroy documents relevant to the Terms of Reference of the Infected Blood Inquiry, whether intentionally or unintentionally? If so please set out:*

*a. What was destroyed;*
*b. Who destroyed it;*
*c. Why they destroyed it; and*
*d. Whether they acted independently or on instructions of others*

142. As explained in my earlier answers, I destroyed or gave away my records, documents and publications relating to the Society between 2009 and 2011 when I moved house, in the belief that I would never need them again.

143. GRO-D

GRO-D

GRO-D

144. GRO-D

GRO-D

145. There is nothing further I can add.

**Statement of Truth**

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

Signed GRO-C

Dated 28 April 2021