Witness Name: Simon Taylor
Statement No: WITN4500001
Exhibits: WITN4500002 -
WITN45000029
Dated: 22.04.21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SIMON TAYLOR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 November 2020.

I, Simon Taylor, will say as follows: -

Section 1: Introduction

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

1. I am Simon Howard Taylor of GRO-C Cornwall GRO-C My date of birth is GRO-C 1956.

Q2. Please set out your employment history, including the positions you have held, the dates that you held these positions, the organisations in which you held these positions and your role and responsibilities in these positions. If it is more efficient, a CV could be annexed at this point.

2. I have severe Haemophilia A and have been co-infected with HIV and HCV as a result of blood products, I believe I was infected with HIV early in 1980 and HCV at some point in the 1970s. This has impacted my education and employment. I attended Lord Mayor Treloar College from 1969 to 1972 and St Edwards School, Oxford from 1972 – 1974, both schools had a number of pupils with severe haemophilia at the time I attended.

3. I hold a BA Hons Durham University 1978. Following graduation from Durham University in 1978, I had a number of jobs in finance in the City of London until 1983. Since 1983, I have held the following positions:

1983 – 1984	Employed by the Social Democratic Party as Organiser for the 1984 elections to the European Parliament.

1984 – 1988	Account Director at Grayling Public Relations (a Public Relations and Public Affairs Consultancy)
1987	Parliamentary Candidate for Hackney North for the SDP
1988 – 1992	Strategy Director and Head of Public Affairs at Ogilvy & Mather Public Relations London
1992 – 2002	Due to increasing poor health, I became a freelance consultant, specialising in reputation and crisis management.
2000 – 2003	Served as member of the Council of the Chartered Institute of Public Relations
2002 – 2004	Head of Press and Public Affairs, for the United Nations High Commissioner for Refugees (UNHCR) based in London
2004 – 2010	Cadbury plc, Head of Corporate Affairs, becoming Corporate Affairs Director for Britain, Ireland, Middle East and Africa, and Global Crisis Director.
2011 – 2013	Visa Europe, Vice President Corporate Communications.
2013 – 2016	Freelance consultant on reputation and crisis management.
2016	Retired

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

4. I set out below details of my memberships relevant to the Inquiry's Terms of Reference.

1985-1988, 1991-1996, 1998 – 2002	Executive Committee member/Trustee of The Haemophilia Society
1988 – 1990	Trustee of The MacFarlane Trust
1992 – 2002	Occasional member of various groups and working parties of the World Federation of Haemophilia and the European Haemophilia Consortium.
2005 – 2011	Trustee of Terrence Higgins Trust and Chair of Trustees (2006 – 2009)
2015 – 2017	Trustee of Lord Mayor Treloar College

Section 2: Previous Evidence

Q4. Please confirm whether you have provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products.

5. I have not provided any evidence or have been involved in any other inquiries, investigations, criminal or civil ligation 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.

Section 3: Your 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.

6. Please note that in my statement the terms "Executive Committee member" and "Trustee" are interchangeable, as are references to "The Executive Committee" or "Trustee Board".

7. Until 1984/5 my perception of the Haemophilia Society (the Society) was that it was focussed on providing information and support to the haemophilia community generally through a small number of local support groups, and through its publications, communicating information on aspects of living with haemophilia, practical help such as small grants, holidays etc. I had very little, if any, involvement with the Society up to this time.

8. It has always been the case that a great many people with haemophilia have been isolated, as it is a rare condition, and is distributed amongst the population generally. This means that most individuals or families would not normally come into contact with anyone else with the condition, and also that most communities would be unfamiliar with the condition and its treatment. Consequently, most schools, GPs, dentists, other health professionals, social services, local authorities and other public bodies had no experience of haemophilia and so were frequently unequipped, and often unwilling, to provide appropriate help and support. For example, it was common for schools to refuse to take boys with haemophilia or for dentists to refuse treating people with haemophilia. Unexplained bruising or injury would lead to unwarranted and distressing involvement by social services. These were the days before the Disability Discrimination Act (1995) or Statements of Special Educational Needs and Disabilities.

9. It was also the case, and it still is to some extent, that whilst there were a number of centres of excellence in haemophilia care around the country, many people were having their treatment from well meaning, but inexpert, haematology consultants with very small cohorts of haemophilia patients, in local district hospitals rather than at Haemophilia Centres where there was a higher degree of expertise.

10. The Haemophilia Society at the time I joined, and going forward, played a crucial role in addressing some of these problems.

Information

11. Through 'The Bulletin' and other publications, the Society gave the community valuable information about treatments and services that they could, and should, expect from their care provider, thus empowering them. The Society was able to help patients know what questions to ask of their health professionals and in many cases demand better care than that which they were receiving.

12. Its groups and meetings provided peer support networks, where individuals and families could meet others in similar situations to their own.

13. It advocated for individuals in specific situations, supporting people with benefit applications or with schools and other institutions which did not know how to respond appropriately to an individual with haemophilia. For example, I believe it produced publications for schools on how to support and integrate a child with haemophilia and any special needs that they might require.

14. At a national level, it sought to educate key stakeholder groups for better understanding, working with professional bodies and government departments.

15. In regards to treatment and care it sought to be the voice of the patient, seeking to improve the quality and range of care and support to all people with haemophilia. In particular it was the Haemophilia Society that drove the Department of Health and Haemophilia Centres in providing "Comprehensive Care" that included, not only high quality haematological expertise in treatment, but also such things as specialist physiotherapy, psychosocial support, and genetic counselling.

16. A later example of this work was the Society document "The Essentials of Haemophilia Care" [Exhibit WITN4500002] published at the end of 1991. This gave guidance to Health Authorities on how to provide these services. This document brought together the needs of people with haemophilia and was a platform for further lobbying by the Society as it sought to continuously improve the quality of life through the products available, such as high purity factor and in due course recombinant products, and also best practice in care, such as the drive for universal prophylaxis.

17. HIV, and later HCV, gave vastly greater impetus to all of the above from about 1984 onwards.

18. The growing realisation of the impact of HIV on people with haemophilia, had a profound impact on all aspects of The Society.

19. The Society at the time I joined was a very small, poorly funded organisation, working in small cramped offices and which had only relatively recently employed its first full time member of staff. It was funded primarily through community fundraising efforts such as raffles, coffee mornings, and sponsored activities by members.

20. The Trustees were then, and throughout the period I was involved, volunteers with normal full time other jobs and mostly were either people with haemophilia or the parent of someone with haemophilia. Many of the Trustees were also infected with HIV and continued carrying out their duties whilst ill, and in some cases until their death.

21. Responding to the HIV impact on the haemophilia community created a huge range of tasks additional to those outlined above relating to the general needs of people with haemophilia.

22. Initially the most urgent need from the community was for information on the threat, and support and advocacy in responding to it. This was particularly in the context of the huge stigma and fear associated with HIV at the time.

23. Reliable information was difficult to obtain, both because it was a new and emerging threat about which little was known, but also in the early days there had been differences in opinion by clinicians as to the impact on people with haemophilia.

24. Amongst the issues that the Society faced were:
    - Patients could not always rely on their treating physicians to give them accurate and timely information on the condition;
    - Much of what information that did exist was targeted at, and developed by, the gay community, and not appropriate for people impacted with haemophilia. Also, the haemophilia community did not want to be associated with the gay community or intravenous drug users;
    - A very great number of the Society's members were fearful that their haemophilia would be seen as a marker for having AIDS with the general public, and so often tried to keep their haemophilia secret;
    - Most significant of all, was the hysterical media coverage of the AIDS epidemic, with lurid stories which generated great distress and anxiety across the whole haemophilia community.

25. The response to these issues was a need for regular and rapid communication of information to people with haemophilia from a trusted and independent source. This became a core function of the Society, through 'The Bulletin', 'Update' and 'Haemofact" newsletters, alongside the creation of such publications as "AIDS and the Blood" by Dr Peter Jones from Newcastle in 1985 and published by the Society.

Introduction and use of safer products

26. A second track of work for the Society was to lobby for the rapid introduction and use of safer products and the security of supply of factor products for all people with haemophilia in the UK.

Campaign for support

27. A third area was to campaign for support for those infected and impacted. This included not only monetary recompense, compensation, and support for potential litigation, but also to try and ensure practical help such as the provision of counselling was available in haemophilia centres, and assistance with benefit claims etc.

Response to the media

28. Finally, there was dealing with the public aspects of AIDS in the media and the stigmatisation of those infected, including children. The Society was inundated with calls from the media whenever a new story about AIDS came out and processes had to be put into place to deal with these. In addition, support had to be given to individuals who found themselves caught up in situations and media storms, such as children with haemophilia and HIV going to school.

29. As the second emerging impact of HCV became clearer over time, all of the above activities also applied and multiplied.

30. I would also draw the Inquiry's attention to the submission by the Haemophilia Society to the Penrose Inquiry in a letter dated 1 November 2011, which I endorse as being an accurate account of the ways of working of the Society in as much as I recall from my tenure [Exhibit WITN4500003].

Q6. The Inquiry is aware that you were an Executive Committee Member from 1985 to 1988, and served as Vice-Chairman and Treasurer from 1991 to 2002. Please confirm and explain what your role and responsibilities were in relation to each tenure and how your role and responsibilities changed over time. If you held any other positions within the Haemophilia Society, please set them out.

31. I first got involved with the Society during 1985 when I offered voluntary assistance, given my background in public relations and public affairs, and I was co-opted onto the Executive Committee around the end of 1985. I was formally elected a Trustee in 1986 and served until 1988. I was re-elected as a Trustee in mid 1991 and served until 1996 when my increasing ill health caused me to stand down. I re-joined the Executive Committee in 1998 and served until 2002

32. At all times I was a Trustee, I acted on a voluntary non-executive basis, with all day-to-day decisions being made by the Society staff, usually in consultation with the Chairman. The Executive Committee normally met every one or two months to discuss and decide major matters and set direction for the staff. Task groups and sub committees would meet between Executive meetings as required by the Chair of the group and relevant staff.

33. In the period from 1985 to 1988, I assisted with handling press enquiries and occasionally acted as a spokesperson, either responding to 'out of hours' calls from the press, or where it was felt that it would be more powerful to have someone with personal experience of haemophilia and HIV to do TV or radio interviews. In due course when resources allowed, the Society retained a public relations agency to handle most calls from the press thus freeing up valuable staff time.

34. From 1985 onwards, including periods when I was not a Trustee, as someone with experience of the media and also working with government, I was consulted outside Executive meetings and sub-committee meetings by the staff and the Chairman

whenever they felt my advice might be helpful on matters relating to media coverage or political matters.

35. As a Vice-Chairman, I deputised for the Chair when required, otherwise for the most part my role as a trustee did not materially change.

36. When I became Treasurer in 1998, I was more regularly involved in providing advice and direction to the staff in between formal meetings, including cheque signing and discussions relating to fundraising and general administration issues for the Society.

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 Policy Committee, Services Committee, the Finance Committee, Publications and External Relations Sub-Committee, the Blood Products Task Group [HSOC0003722] , the Hepatitis Campaign Group [HSOC0003794 ; HSOC0016972] and the International Task Group [HSOC0003722], and the nature and period of your involvement.

37. It was the working practice of the Society to regularly set up sub committees and task groups as needed. Some of these were short term, others were semi-permanent; the names changed sometimes, whilst the function might remain unchanged. All members of the Executive were allocated to a range of committees based on a combination of personal interest and direction by the Chair of the Society depending on skills and experience.

38. I cannot recall details of all the groups that existed, or the period that I was a member of any specific group over the 14 years I served on the Executive Committee.

39. The detailed remit of these groups would change over time, and the Inquiry can ascertain details from Society minutes of meetings.

40. I do not recall specific details of if, or when, I was a member of any of these groups , however my broad recollection is that in general terms the remits were fairly straightforward:

- Policy Committee looked at topics such as blood product safety etc;
- Services Committee was responsible for services to members including publications, information days, support with benefits etc;
- Finance Committee – Finance and administrative matters and fund raising;
- Publications and External Relations – Oversee publications including 'the Bulletin' – at times the Committee also looked at communication with government and politicians if not covered by another committee;
- Blood products task group – to review issues relating to blood products, particularly safety and supply. [HSOC0003722] refers.
- Hepatitis Campaign Group – in conjunction with the staff and our professional advisors (PR and Lobbying) to oversee the campaign for support for people impacted by HCV infection. Minutes of the Hepatitis Task Group 11 Jan 1995 para 3 gives an account of the work of the group. [HSOC0003794]

- Hepatitis Task Group – in conjunction with the staff, and the Manor House Group to gather information on the impact of HCV and advise the Executive Committee on actions.
- International Task Group – remit included relations and working with the World Federation of Haemophilia, the European Haemophilia Consortium (EHC), and twinning with other national haemophilia societies. [HSOC0003722] refers.

Q8: Please confirm whether you were involved in the work of Committee B? If so, please detail the aims and objectives of the Committee and your role and responsibilities on it.

41. Full details of Committee 'A' and Committee 'B' are set out in the Minutes of the Executive Committee meeting dated 1 July 1993 [HSOC0024828] including membership. I was a member of the committee along with other trustees. The committee was Chaired by the late Mr Ken Milne. My recollection was that de facto, Committee 'B' was the Policy and Services Committee by another name. As such I believe the Committee looked at topics such as blood product safety as well as services to members including publications, information days, support with benefits etc.

3.1 The Hepatitis Task Group

Q9. The Inquiry is aware you were involved in the work of the Hepatitis Task Group [HSOC0003794]. To the extent that you have not already answered, please explain what the aims of the Hepatitis Task Group were. Why was it set up at that point in time? Who were the members of the Hepatitis Task Group and how were they selected? Please explain what the Hepatitis Task Group did during the course of your tenure at the Society.

42. My recollection of the work that I did with the Hepatitis Task Group is limited, however I would infer from the minutes that the 1995 Hepatitis Task Group was established to monitor developments in connection with Hepatitis C and develop appropriate member communications and activities.

43. I do not recall specifically why the Group was established at that time, I assume it was because the threat from HCV had become more apparent and urgent. [HSOC0003289] refers to a previous meeting of this group.

44. I do not recall how the members were selected, however in addition to Graham Barker, myself and Mrs Norma Guy from the Executive Committee, there were two representatives of the Manor House Group in order to specifically include representatives of the HCV impacted community.

45. I do not recall what the group did during the course of my tenure, however the minute records proposed actions by the Society including: the holding of Hepatitis days; an article on the Manor House Group for the Bulletin; holding a meeting with MPs; redrafting the Hepatitis booklet; researching into the needs of people with HCV; holding a Women's weekend.

Q10. What role did the Hepatitis Task Group play in the campaign for compensation for people infected with HCV [HSOC0023353]? What (if any) was the relationship between the Hepatitis Task Group and the Hepatitis Campaign Group?

46. I do not recall what role the Hepatitis Task Group played in compensation for people infected with HCV, however it is likely that the work of the Hepatitis Task Group would have informed the work of the Hepatitis Campaign Group which was focussing on campaigns for compensation. It is probable that the Task Group sought to gather evidence for the case to be made to Government, by means of the Campaign, however I have no direct recollection.

Q11. Please outline the relationship between the Hepatitis Task Group and the Manor House Group [HSOC0023353; HSOC0015306]. Please set out any differences in approach and/or actions taken by the two groups.

47. I do not recall specifically what the relationship was between the Hepatitis Task Group and the Manor House Group, however the fact that that the Manor House Group were represented on the Hepatitis Task group, illustrated that their concerns were being taken fully into account.

48. More broadly, and as also stated below in relation to the Birchgrove Group, the Manor House Group was a 'single issue' group focussing on HCV issues and could also become frustrated occasionally that the Society did not devote more time and resources to HCV matters and issues. I seem to recall that the Society gave considerable financial and other support to the Manor House Group.

3.2 HIV Task Group

Q12. The Inquiry is aware you were involved in the work of the HIV Task Group [HSOC0023418] . To the extent that you have not already answered, please explain what the aims of the HIV Task Group were. Why was it set up at that point in time? Who were the members of the HIV Task Group and how were they selected? Please explain what the HIV Task Group did during the course of your tenure at the Society.

49. I do not recall specifically the aims of the HIV Task Group, however I would infer from the minutes that the Group existed to monitor developments in connection with HIV and develop appropriate member communications and activities.

50. I do not recall specifically, however I do not believe that it was newly established at this time and I believe that it had existed for some time previously in some form or other.

51. The group would have been established by the Executive Committee I do not recall the members of the HIV Task Group nor any specifics about their selection. According to the Minutes the membership consisted of myself, Mrs Guy, GRO-D GRO-D GRO-D and individual (redacted) from the Birchgrove Group and Tudur Williams from the Macfarlane Trust (MFT). Mrs Guy, Mr GRO-D GRO-D and myself were Executive Committee members. Mr Williams was the Social Worker

from the MFT. It should be noted that in addition to the individual representing the Birchgrove Group GRO-D was also a leading member of the Birchgrove Group.

52. I do not recall specifically details of the work of the group during my tenure, however as the minutes record, typical activities would have included: liaising with the MFT; dissemination of information relating to HIV; developing and supporting outreach events both by the Society and through others such as the Birchgrove Group; and informing ongoing media and political communications relating to HIV.

Q13. Please outline the relationship between the HIV Task Group and the Birchgrove Group. Please set out any differences in approach and/or actions taken by the two groups. [HSOC0023418; HSOC0023357].

53. The Birchgrove Group was an independent group of people with haemophilia who had been infected with HIV. Originally established in Cardiff, it existed to provide mutual support for its members and also to campaign for improved care and financial recompense for those infected. As such, it was largely a 'single issue' group focussed on HIV, whereas the Society covered the whole range of haemophilia issues and represented the whole community of haemophilia, most of whom had not been infected with HIV.

54. Because of their single focus, the Birchgrove Group could be frustrated at times that the Society was not doing more on HIV issues, however as the minutes show in [HSCO0023357], the Society gave considerable financial, logistical and other support to the Group and there are frequent references to the Group and its work in the Bulletin.

3.3. The Project Team

Q14. It appears that in September 1991 a Hepatitis Project Team was established within the Society [HSOC0003297]. Please explain what the aims of the project team were. Why was it set up at that point in time? Who was on the project team and how were they selected? Please explain what the Project Team did during the course of your tenure at the Society. [HSOC0003289, HSOC0010387 may also be of assistance].

55. I do not recall specifically why the Hepatitis Project Team was established in September 1991, I assume it was to ascertain the current state of knowledge on HCV and its implications for people with haemophilia. The aims and issues of concern to the Society at that time are set out in detail in the letter from Graham Barker on 23 September 1991 [HSOC0003297].

56. My answers to Q 39 below also refers to this 1991 Hepatitis Project Team in more detail.

57. [HSOC0003289] refers to the later Hepatitis Task Group of 1993 referred to above which sets out a series of proposed activities to keep the issue under close observation and proposed a hepatitis awareness campaign for the Society's members.

58. [HSOC0010387] does not appear to reference any relevant matters to this question.

3.4 The Medical Advisory Panel

Q15. 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.

59. I had no direct dealings with the Medical Advisory Panel (MAP) during my tenure that I can recall. As an Executive Committee member, we received feedback from the Chairman Rev Tanner, David Watters or Graham Barker, who were the primary points of contact with the MAP. Regarding its purpose, functions and responsibilities are concerned, the situation is set out in [HSOC0010470] in the report dated November 1991. Prior to this review, I understood the MAP to be a group of leading haemophilia clinicians that were consulted by the Society on an ad hoc basis. I believe that the review recommendations were implemented to put the MAP in a more formal basis.

Q16. 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?

60. None of the members of the Executive Committee or any members of staff were clinicians or scientists expert in haemophilia. Accordingly, we were highly reliant on the MAP for such opinions. Other sources were the general media, information shared from other organisations such as the World Federation of Haemophilia (WFH) or the British Liver Trust, and informal conversations with Haemophilia clinicians who did not happen to sit on the MAP.

61. The Society did not have the expertise or resources to conduct its own scientific research or to review of scientific journals and papers. The MAP consisted of clinicians who were national, and in some cases world, experts in all aspects of haemophilia care. It is my understanding that the nature of haemophilia as a condition made it a complex interaction with other conditions such as hepatitis and orthopaedics, and thus a pure specialist in another discipline might not have the experience or expertise to advise on its presentation in haemophilia. Accordingly the MAP as experts in haemophilia were the most appropriate expert advisors that the Society could call on for advice.

Q17. 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.

62. I do not recall prior to 1991. Following the 1991 review I assume that the process outlined in the paper [HSC0010470] was followed however I had no direct involvement in the selection of members of the Medical Advisory Panel.

Q18. In a brief on the Medical Advisory Panel, dated 7 November 1991 [HSOC0010470] Mr Watters stated that the Medical Advisory Panel consisted "of "favoured" Reference Directors plus, more recently, other Centre Directors". Were you aware that some Reference Directors were "favoured"? If so, what did you understand by it? Who were the "favoured" Directors that were referred to here?

63. I cannot answer specifically, however looking at the list prior to 1991 they appear to be the Centre Directors of the largest Haemophilia Centres on the UK at the time, so the implication I would infer is that "favoured" referred to that fact. This is in contrast to the proposal post 1991, that membership of the MAP should reflect more closely the needs and relevant issues facing the Society, which might bring in subject matter experts, rather than just generalist haemophilia clinicians.

Q19. Please confirm that the Medical Advisory Panel did not meet in person until 1988 [HSOC0010470]. Prior to 1988:

a. How was advice sought from the Medical Advisory Panel?

b. Who decided when and about what matters advice would be sought?

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

d. How were matters discussed by members of the Medical Advisory Panel?

e. Did some members of the Medical Advisory Panel have more influence than other members, and if so, who carried more influence than others?

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

g. How was the Panel's advice recorded once it was received by the Society?

h. In relation to what issues relevant to the Inquiry's Terms of Reference, did the Society seek the advice of the Medical Advisory Panel and what was the advice provided by the Panel on those issues?

64. As outlined above, I cannot confirm this as I had no direct dealings with the MAP. My understanding was that primary contact between the Society and the MAP was by the Chair (Rev Tanner) David Watters and Graham Barker, who would seek advice as was deemed necessary and report back to the Executive Committee as appropriate and relevant to whatever was under discussion.

65. Due to my lack of involvement with the MAP I cannot answer of the supplemental questions (a) to (g) about the how advice was sought, who decided on which mattes advice should be sought or how matters were discussed by members of the MAP, or how advice was communication from the MAP to the Society.

66. In relation to supplemental question (g) I can say that if advice was reported back to the Executive Committee or a working group, it might be recorded in the minutes of those bodies, otherwise I do not know if it was recorded.

67. In relation to supplemental question (h), I cannot answer specifically as I was not involved in those discussions, however I believe that they would have been consulted at various times from 1984 to 2002 on matters including HIV, HCV, blood product safety, treatment protocols, product supply etc.

Q20. Please clarify from 1988:

a. How was advice sought from the Medical Advisory Panel?

b. Who decided when advice would be sought?

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

d. How were matters discussed by members of the Medical Advisory Panel?

e. Did some members of the Medical Advisory Panel have more influence than other members, and if so, who carried more influence than others?

f. Were matters discussed at times other than the in-person meetings of the Panel?

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

h. How was the Panel's advice recorded once it was received by the Society?

i. In relation to what issues relevant to the Inquiry's Terms of Reference, did the Society seek the advice of the Medical Advisory Panel and what was the advice provided by the Panel on those issues?

68. As stated above, I had no direct dealings with the MAP and so I am unable to answer questions 20 (a) – (i) in relation to events in 1988 or question 21. I have no reason to believe that the situation from 1988 to 1992 was different to that outlined in my responses above.

Q21. As far you can recall, please describe:

a. The extent to which the Haemophilia Society relied on its own judgement when deciding whether or not to formulate policy on the basis of the Medical Advisory Panel's advice;

b. All examples, relevant to the Inquiry's Terms of Reference, of when the Society did not follow the Medical Advisory Panel's advice;

c. All examples, relevant to the Inquiry's Terms of Reference, of when other members of the Medical Advisory Panel disagreed with the advice of the Chair of the Panel;

d. All examples, relevant to the Inquiry's Terms of Reference, of when the Haemophilia Society did not follow the advice of the Chair of the Medical Advisory Panel.

69. As above, I cannot recall specific examples of when the Society relied on its own judgment rather than advice from the MAP, however we were very clear the MAP was an advisory panel, and that the Society would make its own policy and decisions as it felt fit.

Q22. In 1991, the Haemophilia Society conducted a review into the workings of the Medical Advisory Panel. Could you please provide examples of circumstances, relevant to the Inquiry's Terms of Reference, of how the below concerns arose [you may be assisted by considering HSOC0010277]:

a. The representatives of the Society and the members of the Medical Advisory Panel felt disappointed with the substantive outcomes of their meetings;

b. The Society representatives felt that it was sometimes difficult for the Medical Advisory Panel to, " take off their Centre Directors' hats and give independent advice";

c. The Society's representatives felt that the meetings of the Medical Advisory Panel risked a lack of independence and gave rise to a " false consensus view " of the members who were also part of the Centre Directors' Organisation.

70. I cannot recall specific examples because as previously stated I did not have direct dealings with the MAP. However, I do recall the general feedback that led to the questions raised in (a) – (c) which I set out below.

71. There was a belief by the Society that it desperately needed independent, unbiased, expert medical and scientific advice on the huge issues facing the Society. Conversely, there was a belief amongst members of the MAP that it saw itself as representing their Haemophilia Centres to the Society. Consequently, issues such as the cost of new products, concerns about potential liability and legal actions, and the innate conservatism of many of the clinicians, mitigated against them giving honest independent advice to the Society. There was a view that they tended to: 'cover their backs' by taking an overly conservative view of emerging threats; prioritising issues such as costs and funding; and avoiding breaking the 'consensus view' of their peers.

72. My understanding was that individual clinicians, who may or may not have been on the MAP, were more likely to give genuinely impartial, and helpful, opinions on an "off the record" basis in discussions with the staff and other individuals outside formal MAP meetings and consultations.

73. I would like to take this opportunity of highlighting the outstanding help and support given by Dr Peter Jones from Newcastle in taking the lead in advising the Society in the early days of the HIV epidemic.

Q23. Please describe how the purpose, function and responsibilities of the Medical Advisory Panel changed (if at all) after this review. Please explain whether Terms of Reference came into being [see HSOC0010470].

74. I believe that the output of the review as outlined was implemented, with the revised purpose, function and responsibilities as set out in [HSOC0010470]. However as

previously stated, during my tenure at the Society I did not have direct dealings with the MAP.

Section 4: Communication and Dissemination of Information by the Society

4.1 Knowledge of Risk

Q24. When you first joined the Executive Committee of the Society in 1985:

a. What did you know and understand about the risks of the transmission of hepatitis from blood and blood products? What were the sources of your knowledge? How did your knowledge and understanding develop over time? [You may be assisted by HSOC0015185].

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

75. a. In 1985 my knowledge of HCV was solely that of a patient. I recall over the years having been told by my doctors that infection with hepatitis (B and NANB) was a normal aspect of treatment with blood products but that the implications were not likely to be serious. This view prevailed until about 1995, when it started to become clear that the implications of HCV was more serious for some.

76. My knowledge of HCV, as it developed, would have reflected that of the Executive Committee as a whole and was based on the advice that we received from the MAP and others as the best clinical and scientific experts in haemophilia care in the country.

77. [HSOC0015185] is a timeline relating to the Hepatitis campaign, rather than the knowledge of the Society relating to Hepatitis C from a clinical perspective. The correspondence and publications from clinicians over time would give a better understanding of the state of the Society's knowledge over the period, for example the 1991 correspondence and conclusions in [HSOC0003297] also referenced elsewhere and the article in The Bulletin in May 1991 [Exhibit WITN4500004] by Dr C Hay and later the article by Dr M Makris in The Bulletin of October 1994 [Exhibit WITN4500005].

78. b. My knowledge of HIV was based on being a reasonably well-informed patient. Most of my information had come from the general media, TV and press articles and some Society communications. Specifically, there had been a TV documentary in 1982/3 that highlighted AIDS as a growing risk and this had made mention of the high risk nature of blood donation in the United States. Following this documentary, I had written to Dr Charles Rizza at the Oxford Haemophilia Centre, where I had been treated since childhood, asking if I should be concerned. I recall his reply as being along the lines of the risk being very small.

79. As more media articles emerged, particularly from 1984 onwards, it became very clear to me of the extraordinarily high risk posed by HIV to those of us who had used factor concentrates over many years. The lengthy interview I gave to Simon Garfield in chapter 4 of his book "The End of Innocence" [ARCH0002893_004] is an accurate reflection of my personal circumstances and knowledge at the time. As stated there, in 1984 when I read a press article that in the US it was assumed that everyone who had used commercial blood products was infected with HIV, I knew that I would be as well.

80. As time passed, and after I joined the Society, I learnt more both as a result of the Society's work and as someone living with HIV.

Q25. In chapter 4 of the book The End of Innocence by Simon Garfield [ARCH0002893_004], it states that "there was also a strong belief that the companies producing the blood concentrates could have done much more to protect their supplies far earlier than they did. 'They could have screened for hepatitis' says Simon Taylor, now an official for the Haemophilia Society. Most of the donations infected with hepatitis were later also found to be infected with HTLV-III. Also heat treatment products had been developed but hadn't been implemented and these had been shown again to be effective against hepatitis. So, we could have used hepatitis as a sort of surrogate marker for HIV. If they'd done that, we probably wouldn't have had anything like the problems we did and do. However, it's always easy to be wise after the event". Please answer the following questions:

a. Is this an accurate representation of what you said at the time?

b. Is this something that you still consider to be correct?

c. When did the Society become aware of the need to screen for hepatitis?

d. How (if at all) was this communicated to pharmaceutical companies and/or the Government?

81. a. Yes, it is.

b. Yes, it is. However, to expand, the "we" referred to, was the UK government, medicines regulators and all those responsible for the importation of blood products to the UK.

Further, by screening for Hepatitis in the 1970s and early 1980s, I was referring to Hep B, as at the relevant time I believed that there was no test for Non A Non B hepatitis.

Finally, these comments were made with the benefit of hindsight more than ten years after the events and relate to a desire for actions that should have been taken from the 1970s onwards.

c. I do not know if anyone in the Society had this view prior to 1984.

d. As indicated above, these are actions that I believe, with hindsight, should have been taken by the Government, medicines regulator and the pharmaceutical

companies from the 1970s onwards. I was not involved with the Society prior to late 1985 but I do not believe that the Haemophilia Society during the 1970s and early 1980s had the staff or expertise to assess this risk nor communicate it to anyone.

Q26. In a meeting of the Executive Committee dated 12 November 1987 [HSOC0029476_072], you "highlighted the necessity to get a general consensus view of the Centre Directors in relation to the life expectancy of people with haemophilia who are HIV antibody positive. It was agreed that sounding should be taken with the Medical Advisory Panel in the first instance." Why was it important to obtain this information? Was a response received by the Medical Advisory Panel?

82. This information would have been an important argument in the campaign to Government, MPs and the media, to gain public support for people infected with HIV. I do not recall if an answer was forthcoming from MAP.

Q27. At a meeting of the Executive Committee dated 31 January 1996 [HSOC0029689_002], Graham Barker reported that a solicitor, Graham Ross was "in possession of documentation which describes the purposeful running down of the fractionation centre in Elstree. He claims that if this had not been done then heat treatment processes to remove HCV would have been developed sooner."

a. When did you become aware of this reported information?

b. What was your view of the matter at the time?

83. a. I do not recall this report nor do I recall that I was aware of this information before this meeting.

b. I do not recall.

Q28. 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?

84. I do not recall. A close reading of the Executive minutes should inform the Inquiry as to the answers to this question.

Q29. To the best of your knowledge, what actions did the Haemophilia Society take in relation to the risk of transmission of vCJD via blood products? What did the Haemophilia Society communicate to its members with regard to the risk of transmission of vCJD? What representations (if any) were made to Haemophilia Society members, the Government or the UKHCDO in relation to these risks? What was their response?

85. I do not recall, my response to Q28 also applies.

4.2 Communication to Members

Q30. 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. Did you write any articles for the Bulletin or Society publications?

86. The Bulletin and 'Update" were concerned with reporting all aspects of the Society's work, and included, for example, articles related to fundraising by local groups, reports on advances in treatment or aspects of living with Haemophilia, information about campaigns as well as many other topics. The Bulletin was normally circulated by post to all members three or four times a year, "Update" would be sent out on an ad-hoc basis between editions of Bulletin if there was important information to be shared. The content of these were decided on by the Editorial Board which consisted of the Chairman (Rev Alan Tanner) and the Editor Clive Knight, and subsequently Andy Cowe from the beginning of 1988, I would not normally be involved with content.

87. The staff would also make suggestions as to content as would individual members of the Executive and others.

88. 'Haemofact', 'Campaign Update' and other such documents were ad hoc publications produced in-house to get time sensitive information to members. These would normally be written by members of the staff involved with campaigns or issues i.e. David Watters and/or Graham Barker or Jonathan Cooper. Copy for these may have had sign off from the Chairman or another member of the Executive Committee, but I do not recall specifically and I would not normally be involved with content.

89. I recall having written occasional articles for the Bulletin which would have been 'bylined' as coming from me, however these generally related to issues outside the Terms of Reference of the Inquiry.

Q31. 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).

90. I do not know as I was not responsible for the selection of articles, however it was normal and routine for articles on clinical and scientific matters by haemophilia clinicians and other clinical specialists to be included in The Bulletin, so as to keep members up to date on developments in aspects of haemophilia care.

Q32. 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).

91. As per Q31, I do not know as I was not responsible for the selection of articles. I do recall that highly exceptionally there might be an article about a pharmaceutical company. It was believed that on a limited basis, members would be interested in the organisations that produced the products they used on a daily basis. Similarly, there may have been occasional articles about new products from pharmaceutical

companies. As a patient, I believe that this was useful information for us to help us understand our treatment.

Q33. How did the Haemophilia Society select or identify contributors and interview subjects for the publications? Specifically, in relation to publications which gave medical and/or other opinions about the safety of blood products and the risk of infection, how were the contributors for such articles? What, if any, were the criteria for someone to be able to write an article for the Haemophilia Society's publications?

92. As above, I do not know as I was not responsible for the selection of articles.

Q34. To what extent (if any) did the Haemophilia Society verify medical and scientific information and/or opinions provided by contributors to its publications? If verification took place, please describe the process by which this occurred.

93. As above, I do not know as I was not responsible for the selection of articles. However more broadly, the Society did not have the resources or expertise to independently verify medical or scientific information that came from prima-facie reputable sources and leading experts in their fields.

Q35. 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.

94. As Trustees, we did not receive any such individual inquiries, they would have been dealt with by the staff of the Society, David Watters or Graham Barker. My understanding was that individuals were always referred to their treating physician and that the Society and its staff would never give individual clinical advice.

95. Society publications contained numerous articles addressing issues relating to the safety of blood products, but as I was not directly involved in the preparation of these articles, I do not know what the review processes might have been.

96. I would make a general point that the haemophilia clinical community would not have been shy of letting the Society know if they believed that we had published something that was incorrect and/or misleading, and I am not aware of many instances of such disagreement. The debate over high purity products [Bulletin November 1991] [Exhibit WITN4500006] was one such example and in these cases a range of points of view would be published, I would consider this to have been a healthy and transparent debate. See also [HSOC0010387] minute no. 28.6 that makes these points.

Q36. In a meeting of the Executive Committee dated 12 November 1987 [HSOC0029476_072], you said that the Society "should produce a pamphlet on POSITIVE LIVING on similar lines to that already produced by the Terrence Higgins Trust. It was agreed that PIER should draft this document and refer it to T&C for their consideration." Was this pamphlet produced? If so, who wrote it? Who was it disseminated to?

97. I do not recall if it was produced.

Q37. Prior to 1993, 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.

98. In respect of (a) – (c), I do not recall, save for articles in the Bulletin and clinical speakers at Society meetings as referenced above in Q24. A close reading of the Society minutes and publications should give the Inquiry more information.

Q38. Considering your answer to question 37, what was the basis for the communications and advice provided by the Haemophilia Society to members about Non-A/Non-B Hepatitis/ HCV during your tenure? Specifically:

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

b. Who provided that advice?

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

d. Who, within the Haemophilia Society, sought any such advice and who did the medical professional provide the advice to?

e. What was their advice in relation to each of the communications you have set out in answer to question 37 above?

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

g. Please explain whether the Haemophilia Society also received advice from other medical professionals, what that advice was and, if it conflicted with the published advice, why it was not followed.

99. As above and in response to (a) – (g), I do not recall in any detail. However, examples of the medical background to any articles or communications would have included articles such as that by Dr Charles Hay in the Bulletin of May 1991 [Exhibit WITN4500004]; the letters from experts [HSOC0003297] in November 1991; the lecture given by Dr Lee at the AGM in 1991 as reported in the Bulletin August 1991 [Exhibit WITN4500007]; the article by Dr Makris in the Bulletin in 1994 [WITN4500005] etc. It is probable that the Medical Advisory Panel also gave advice,

however I am not aware of this. In addition, as referenced elsewhere, the Society organised a series of Hepatitis awareness events at which a leading clinician, not from the local haemophilia centre, would speak and answer questions from members.

Q39. In a meeting of the Executives Committee, dated 14 November 1991 [HSOC0010385], " Mr Milne reported that the Project Team consisting of Mr GRO-D ***and Mr Taylor, along with Mr Barker and Mr Watters, had completed the brief on hepatitis. Mr Taylor told the Committee that, having contacted experts in the field and having received comprehensive reports on the current thinking on the subject, 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. Mr Taylor proposed that a fact sheet on hepatitis be prepared and a request made that the Project Team be discharged from its duties; the Committee agreed, and thanked Mr Taylor and Mr*** GRO-D ***for the useful work they had accomplished." Could you please clarify:***

a. Which medical experts were contacted? How did you decide who to contact?

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

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

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

e. How did the Project Team reach this conclusion and how long did it take to reach the conclusion?

f. Was there any disagreement within the Team in reaching this conclusion?

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

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

100. a. [HSOC0003297] covers this in some detail and lists which medical experts were consulted being Prof Preston, Dr Hay, Dr Lee and Dr Mayne. I do not recall how they were selected but they were all haemophilia clinicians who had shown an interest in issues relating to hepatitis.

b. The correspondence in [HSOC0003297] sets out the advice received. The responses are very detailed however key extracts that would have informed the Society's views would have included:

Dr Hay: "The majority of these patients, if biopsied, would have been shown to have chronic persistent hepatitis, a mild and usually non-progressive form of liver disease unlikely to give problems."

"For older patients, only qualified reassurance can be provided that the majority, probably of the order of 80-85%, will never suffer any problems from liver disease."
"I think you should be very wary of making too much of a fuss about it and giving it too high profile since this will just cause distress, and since liver disease is a much smaller problem than HIV that most people affected will not suffer any problems from it."

Dr Lee: "I would say at the outset, that you have raised many unanswerable questions."
(re treatment) "I think the other important thing about hepatitis C and treatment is that because of the slow progression in a way, we can afford to wait until the treatment is more established."
"I think one has to be careful all the time that one is not alarming patients unduly whilst at the same time, keeping them informed."

c. As [HSOC0003297] shows, advice was sought primarily by letter, it indicated Mr Barker had meetings with Dr Lee and possibly Prof Preston, however I do not know if any minutes were taken of those meetings.

d. A non-expert reading of the three letters in [HSOC0003297] appears to provide broadly similar opinions.

e. I do not recall specifically how the Project Team reached its conclusions, however the conclusions would have been based on the research carried out by Graham Barker, including the correspondence and meetings previously referred to, and decided at its next meetings, which I assume was sometime between the date of the memorandum 30 October 1991 and the meeting of the Executive Committee on 14th November 1991.

f. I do not recall specifically but I believe it unlikely.

g. I do not recall specifically, but Mr Barker as Policy Manager had undertaken the research, and as such was the Society's subject matter expert, and so his influence would have carried more influence than others in all likelihood.

h. I cannot recall precisely, however I would suggest that it needs to be seen in the context of the HIV epidemic at the time.

101. In 1991 if you were positive for HIV then there was a 100% probability of death at some point over the next few years. The press and media in many of their comments, were

positioning "HCV as the new AIDS" and so it was essential to reassure members that, based on the evidence available at the time, and as shown in the correspondence [HSOC0003297], the risks and likely outcomes for most were vastly different from HIV and AIDS.

102. Bluntly, the Society understood that some of our members, who had been infected with HCV but not HIV, believed that they were definitely going to die, when the medical evidence at the time did not show that this would be the case.

103. Dr Hay's article in The Bulletin of May 1991 [WITN4500004] had stated "it is usually not an active concern since most will have recovered or will have mild liver disease. A minority of patients are at risk of more serious problems and may require treatment with Alpha-Interferon." Thus, the belief at the time, was that the relative risks between HIV and HCV were not proportionate.

104. Further, again as a result of media reports and a lack of understanding of HCV its implications and transmission, there were fears from our members of being stigmatised by the public in the same way that people with HIV were.

105. I do not recall that this resulted in any changes in planned communications to members other than the production of the proposed fact sheet mentioned.

Q40. In a meeting of the Executive Committee held on 16 March 1994 [HSOC0015303] , you reported that a pilot Hepatitis Day held on 12 March 1994 at Hotel Ibis, Euston, was attended by about 70 people, with evaluation forms handed out at the meeting to get feedback. What was the purpose of the event? How was the feedback from attendees used?

106. This would have an open information event for members with a range of speakers on the topic of hepatitis, however I do not recall the exact details. The purpose was to provide people with up to date information on hepatitis (in particular HCV) and to encourage them to go back and discuss this with their own centre staff.

107. Notes of the earlier Hepatitis Task Group meeting on 17 September 1993 [HACO0003289] sets out the format for the proposed meetings. "A format was agreed whereby a series of meetings could be held at seven venues throughout the UK (Perth, Craigavon, York, Manchester, Birmingham, Bristol and London were suggested) where medical and legal aspects of hepatitis would be presented at a three hour meeting which would also include time for Q&As."

108. The subsequent meeting of the Services Committee on 30 June 1994 at para B94.54 [HSCO0003357] gives an account of subsequent Hepatitis meetings and gives an account of the purpose of them and that the evaluation forms showed that attendees had gained useful information and understanding from these meetings that they had not been getting from their own centres.

Q41. In the Bulletin dated 1 April 1994, an article titled "Hepatitis C – A cause for concern?" was published [RFLT0000071]. To the best of your knowledge, how (if at all) did the Haemophilia Society verify the accuracy of the statements made by yourself in

this article? Please set out precisely who within the Haemophilia Society verified the accuracy of the statements; who they spoke to and/or on what materials they relied; how that information was recorded; and who decided, and how the decision was taken, that this was proper information to include in the Bulletin.

109. The article is a report of a talk given by Dr C Lee at the Hepatitis meeting held on 12 March 1994 referred to above. I and others from the Society would have been present at the meeting and taken notes of Dr Lee's address. If it had been inaccurate in any way, I am confident that Dr Lee would have let us know.

110. Whilst I cannot recall any specific decisions about including a report of Dr Lee's presentation in The Bulletin, given only a limited number of members would have been able to attend a meeting in London, it would have been perverse not to share some of the information from the keynote speaker at the meeting more widely.

Q42. Please detail any activities the Haemophilia Society conducted with the purpose of disseminating information to healthcare professionals during your tenure. If this changed over time please detail when and why.

111. One of the core objectives of the Society was the promotion of the highest possible standards of care for people with haemophilia in the UK. In order to achieve this, the Society occasionally produced policy statements, particularly when it had a view on what should be the "Gold standard" of care at the time. These would be directed at health professionals, government and civil servants responsible for commissioning and paying for care.

112. In addition to the various policies referred to elsewhere in the work of the Inquiry, the best example of this, was the development of the document "The Essentials of Haemophilia Care" [Exhibit WITN4500002] published in 1991. I believe that this document was the first time that a detailed standard of the care that all people with haemophilia should expect from their centres had been produced, I also believe that this may have been a world first.

113. Many healthcare professionals received Society publications such as the Bulletin, which regularly included articles and papers from clinicians and scientists, so as to inform the haemophilia treating community more widely on new developments.

Q43. 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?

114. I do not recall if I was a Trustee at the time of the memo (April 1991), however as I have said above, the promotion of the highest standards of care was a central role of the Society and it was undoubtedly the case that some of the audiences mentioned lagged behind in their knowledge and adoption of best practice in haemophilia care. I

do not have knowledge of direct lobbying of health professionals or staff in small centres however.

Q44. In the Minutes of the Board of Trustees Meeting held on 9 May 1996, "it was reported that the Medical Advisory Panel was critical of the section in the Society's Hepatitis report that contained recommendations for action by Centres. It was felt that it was inappropriate for the Society to comment on the services and treatment provided by Centres as this was a matter of clinical judgement. Some felt that it was wrong for the Society to interview their patients" [HSOC0029689_004]. Please comment.

a. Were there other circumstances in which the Haemophilia Society did make "recommendation for action by Centres " or seek to influence UKCHDO policy and practices?

b. To the best of your knowledge, why did the Haemophilia Society interview "patients"? Were there other circumstances in which the Haemophilia Society would interview patients? If so, please provide details as to the purpose of these interviews.

115. I believe that it was absolutely the role of the Society to advocate on behalf of its members in seeking to receive the best possible care, and to encourage its members to ask their centres for this.

a. I do not recall specifics, however our policies and campaigns, such as for the wider use and funding of recombinant products, use of high purity products and prophylactic treatment would all be examples where the Society would have called upon the UKHCDO to adopt as policy and practice.

b. I do not recall the Society as having 'interviewed' patients, however over the years the Society regularly conducted member surveys, including on their satisfaction of the treatment they were receiving, and received feedback at Society member events, in order to inform its policies and actions. This continues to this day.

4.3 Communication with pharmaceutical companies

Q45. 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.

116. Funding from pharmaceutical companies of patient groups was common at the time across a wide range of health conditions, many health based charities received funding of this kind. More recently restrictions have been placed on such funding by the Association of the British Pharmaceutical Industry (ABPI), but during the 1980s and 1990s this was considered normal practice.

117. My view of the blood product companies, which I believe was shared by the Society generally, was one of wary cynicism. We were only too aware that it had been largely their products, and their plasma collection practices, that had caused the infected blood epidemic amongst the haemophilia community. As a consequence, we did not

trust them, however we felt little compunction in seeking money from them to help respond to the problems that they had in large caused.

118. Before the HIV epidemic the Society's main sources of income was community fundraising including: the Christmas raffle; an annual Ball; fundraising by local groups; individual fundraising by members etc. As the scale of impact on the Society's work in supporting the community grew, a considerable amount of money was received from the Government in the form of 'Section 64' grants. In addition, a number of pharmaceutical companies provided, on request, contributions to activities and events, however I do not believe that the total of pharmaceutical company contributions ever became a significant proportion of the Society's funding.

119. The normal procedure as I recall, was that the Society would decide to hold an event, such as a members' conference or an information day, and then approach the pharmaceutical companies to see if they would make a contribution to the cost. I do not recall any examples of the companies approaching the Society with a request to undertake any activity in return for financial support.

120. I do not recall in detail all activities that companies gave contributions to, they were in main member events as outlined above or participation in WFH or EHC meetings. A number of companies made financial contributions to publications such as The Bulletin.

Q46. Was the Society's relationship with BPL different to its relationship with the pharmaceutical companies? If so, please explain how.

121. My recollection of the Society's view of BPL was slightly different to that of the commercial companies, in that we viewed it as well-meaning, but incompetent. This was based on the repeated failures of BPL to meet targets for the implementation of self-sufficiency and the introduction of improved products. Further, we were aware that as a Government agency, its scope to provide support for Society activities was much more limited.

Q47. In an internal memo, staff at BPL noted that they had " one eye on the Society's substantial research funds!" [BPLL0007355] . Please explain what research funds were held by the Society and how it was determined that they should be distributed What monies were provided to BPL over your tenure? What benefit did the Society derive from the relationship with BPL? Were research funds provided to any of the pharmaceutical companies?

122. The Society held funds of up to £100,000 designated for research, however I believe most of the time the value of this fund was in the range £50,000 to £30,000

123. These were normally funds that had been raised specifically for haemophilia related research or had been legacies designated as such. The Society generally gave out relatively small grants of up to £1-2,000 to help on a wide range of projects or also to improve facilities for patients at haemophilia centres.

124. My recollection is that requests for funding would be made to the Society, they would be reviewed by the staff and probably the Chairman, and then a recommendation made to the Executive Committee.

125. To the best of my knowledge, we never gave any money to BPL, or to any of the pharmaceutical companies, from the research fund or anywhere else, this would have been perverse given their financial standing compared to the Society.

126. There were two primary benefits of having a relationship with both BPL and the pharmaceutical companies. One benefit was the ability to gain an understanding of their products and processes, which was valuable as the Society sought to build its own knowledge and understanding of product safety and innovations. The other was financial, as outlined above, in that they were able to make contributions to events for our members that might not otherwise have been possible.

Q48. 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.

127. I cannot recall specifics, but generally the points of contact would have been the Society staff, i.e. David Watters or Graham Barker, and this would have been the route of communication for any financial requests. Representatives of the product manufacturers might attend member events, and trustees such as myself would meet them on such occasions.

128. My recollection is that all funding from pharmaceutical companies was needs led, in that the Society would decide on a project or activity, and then seek funding for it. I am not aware of any instances of companies instigating or proposing activities that the Society should undertake.

Q49. 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?

129. Raising funds for the Society's services and activities was always a high priority, especially as need rose dramatically from 1984 onwards. As I recall, at various points we sought to professionalise fund raising and employed a range of consultants and part time staff to assist with this, with varying levels of success. I do not recall any specific factors over time that influenced the contributions made by the blood product manufacturers.

Q50. Please explain any differences in the Society's relationships with the different pharmaceutical companies. For example, were there some pharmaceutical companies that donated more, in terms of frequency and/or amount, than other pharmaceutical companies, to the Haemophilia Society? If so, which ones? Did they have different expectations of the Society? Did they want to fund different activities or functions?

130. With regard to the relationships between the Society and the manufacturers, I would refer to my comments above in answer to Q 45 and Q 46. I do not recall specifics relating to donations, nor do I recall any significant differences in the relationships with the Society. As stated previously, my recollection was that requests and proposals for funding for activities came from the Society, not from the companies.

Q51. 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?

131. I believe guilt might have had a lot to do with it. I have no knowledge of any specific motivations and expectations by any of the companies. I expect they believed that by supporting some of the Society's activities, they might ward off criticism of their past actions, but that is speculation on my part.

132. I do not believe that there was any expectation that the Society would provide anything in return.

Q52. A number of the Haemophilia Society Bulletins record which pharmaceutical company funded the production of the Bulletin. Was that record a requirement of their funding? What was agreed in this regard? How was this agreed?

133. I am not aware of any such agreement or requirements of the funding. I believe that the acknowledgment of funding was a matter of good manners as is normal in such situations.

Q53. 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.

134. We did not seek to assist the pharmaceutical companies to promote their products and or public image.

Q54. 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.

135. Not to my knowledge.

Q55. 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.

136. Not to my knowledge.

Q56. In an Executive Committee meeting dated 14 January 1988 [HSOC0029476_076], Ken Milne reported that "meetings would be held with representatives of the various pharmaceutical companies over the coming months. It had been decided to hold small meetings, rather than open meetings for all pharmaceutical companies. Ken Milne reported that he would be joined by Simon Taylor, from Publications and External Relations, in those meetings, on account of the External Relations role that would develop from the work of the Blood Products Committee. " Please outline the aim of these meetings. What representations were made by the Society to the pharmaceutical companies? What did pharmaceutical companies seek to obtain from the Society?

137. I do not recall these meetings, and I do not believe I actually attended any, as my work commitments at the time did not allow time for non-work related meetings. I believe however, given the context of the wider minute, that these meetings were related to the desire by the Society to better understand the safety of blood products and that they were initiated by the Society.

Q57. At a meeting of the Executive Committee dated 1 July 1993 [HSOC0024828], it was reported that Blood Products Laboratory delayed informing the Society that a batch of plasma had been contaminated with HCV. You stated that "the issue of Hepatitis should be considered in detail by Committee B. There were indications of widespread concern and it was time for the Society to issue a clear statement of policy on the subject." Please explain what the context of this minute was.

138. It was, and remains to this day, normal practice for all pharmaceutical companies to inform patient groups if there is a problem with the medication that is used by that particular community. To the best of my knowledge there was no specific agreement that this kind of communication would take place, but there was and remains an expectation of such communications by all medicinal manufacturers. I do not recall if it changed our view of BPL as outlined above in my answer to Q 46.

139. I believe the second paragraph of the minute refers to the issue of hepatitis generally, rather than the BPL incident referred to above, and the continuing concern members had about the implications of hepatitis infection, leading to the many actions taken by the Society in relation to this issue and referred to elsewhere.

Q58. In an Executive Committee Meeting dated 16 March 1994 [HSOC0015303] you reported that you and Mr Barker would be visiting some Centres and Pharmaceutical Companies. You also suggested that members of the Executive may wish to visit BPL at Elstree. What was the purpose of these visits? What took place on the visits? Why do you think that the pharmaceutical companies enabled you to visit? Did you disseminate information from those visits to the Society's members? If so, what did you tell them? Did the pharmaceutical companies seek input from you about their products when you visited?

140. My recollection is that these meetings were to gain information and understanding about the manufacture and safety of products. I recall that in fact I only attended one such meeting or visit during my tenure, which was a visit, with others from the Society but I do not recall who else, to BPL to be shown the facility where factor products were made. The purpose of the visit was so that we understood the manufacturing process and could see the Good Manufacturing Practice (GMP) and safety measures in place.

141. I presume that the companies wanted to build confidence in the safety of their products.

142. I do not recall disseminating information to our members about the visits.

143. I do not recall that the companies sought input from us about their products when we visited.

Q59. To what extent did the Haemophilia Society rely (if at all) on communications from pharmaceutical companies for assurances or opinions on the safety of blood products? If so, please provide as much detail as possible on the points of contact in pharmaceutical companies, the advice provided, the issues raised, and the frequency of these communications. [BPLL0002037 may assist you.]

144. I have no knowledge of any such communications.

Q60. In the Update of August 1987, on the front page there is an article about genetically engineered Factor VIII and "highly purified" Factor VIII produced by Baxter Travenol [RFLT0000086]. Who wrote this article? Where did the information about the safety of the products come from? Was that information checked with the Medical Advisory Panel? If so, please set out what their advice was. If not, was it checked with any other medical professional?

145. It would have been a matter for the Editorial Board of the Bulletin who were also responsible for the production of 'Update'. However, such a development in haemophilia treatment was at the time truly revolutionary, and would have been of great interest to the haemophilia community. I do not know if it had been checked by anyone from MAP as I was not involved in the production of publications such as The Bulletin.

Q61. In a letter dated 15 July 1992, Graham Barker wrote on behalf of the Society to Norman Pettet of Armour Pharmaceutical and referred to a discussion about writing to " key people in the health authorities and individual hospitals responsible for purchasing blood products " [HSOC0002604]. Were you aware of those discussions and or correspondence? If so please explain what they were about. Were letters sent to health authorities and individual hospitals? If so, please explain what the Society was requesting and/or lobbying for.

146. I do not recall this and have no information about this or any other correspondence. I believe that the purpose of this would have been to ascertain by the Society the relevant contacts in order to be able to make representations to Health Authorities and hospitals asking them to fund the purchase of high purity products.

4.4 Communication on Hepatitis C

Q62. To the best of your knowledge, what information and advice did the Haemophilia Society provide on:

a. The risk of Non-A Non-B Hepatitis/ HCV infection from blood products. Please detail the method of communication, details of the information provided and provide copies of

publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how;

b. The health implications of Non-A Non-B Hepatitis/ HCV infection. Please detail the method of communication, details of the information provided and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how; and

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

147. I do not recall specifically, and I do not possess any relevant documentation. Please also see my answers to Q37 and other questions as above.

148. I believe that The Bulletin, 'Update' and other publications, together with other member communications, member conferences and seminars communicated the Society's knowledge and understanding at the time in a full and comprehensive manner. In all cases we would advise members if they had concerns, to consult their Centre Director or treating physician.

Section 5: Relationship with the Government

Q63. The Inquiry is aware that you played a key role in relation to public relations and lobbying [HSOC0019923_016]. Please identify the extent of your role and involvement with regard to the Society's representations to the Government,

149. My role was primarily advisory. I believe I had an important role in proposing ideas and plans for initiatives to further the aims and objectives of the campaigns through representation advocacy, lobbying and working with the media.

150. I was also in a position to be able to explain as needed, to other Executive Committee members and the staff, how media, political and governmental processes worked and where effective points of leverage might be. I also at times counselled against proposals which I thought would be either counterproductive or would fail.

151. For much of the period in question until 1992, I was in full time employment and thus generally did not have the time to attend personally meetings with politicians, civil servants or ministers, which in any case were led normally by the Chairman Rev Tanner and David Waters or Graham Barker. It was highly unusual for other Executive Committee members to be party to such meetings.

152. I provided a considerable amount of strategic advice, particularly assisting with the drafting and reviewing of campaign materials, to ensure that they were compelling and had maximum impact.

153. I also acted as a spokesperson for the Society, when it was considered useful to be able to field an individual with direct lived experience of infection with contaminated blood products and undertook a number of TV and Radio interviews. After a while, the

Society employed a public relations agency to handle press calls, but prior to this I was regularly 'on-call' at evenings and weekends to take press calls when the Society's office was closed.

154. The Society had the pro-bono services of a leading lobbying company GJW, for the HIV campaign [see Exhibit WITN4500008], and I believe it was helpful for them to have an individual who understood the lobbying process as one of their contacts in the Society.

Q64. 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?

155. The Society developed over time a considerable range of contacts with Government and individuals in public office. It is my understanding that prior to about 1984, contact had been limited to a relatively small number of officials and junior ministers in the Department of Health and these relationships were focussed on the supply of products and principally the issue of self-sufficiency and the development of the facilities at BPL to provide this.

156. When it became clear that we would be calling upon the Government to take action on a wide variety of fronts, particularly support for those infected, the Society started a major campaign of engagement and the recruitment of supporters amongst MPs and also sympathetic journalists.

157. The Society asked all its members to contact constituency MPs and ask for their support for the campaign, and also to feed back to the office any responses, so that the office could maintain a list of supportive MPs.

158. The General Secretary and the Chairman directly contacted government departments to seek meetings with ministers and officials.

159. Over time an 'All Party Parliamentary Group' was formed of MPs and members of the House of Lords and many of these were tireless in their efforts in advocating on behalf of the Society.

160. All contact and relationships were managed through the General Secretary David Watters, and also later Graham Barker, who would report in the first instance to the Chairman Rev Tanner. Virtually all meetings with ministers, officials and MPs were with either David Watters, together with the Chairman, or Graham Barker, together with the Chairman. It would be highly unusual for any other members of the Executive Committee, including myself, to have any direct communication or contact with ministers, officials or MPs.

5.1 Campaign for Compensation for HIV/ AIDS

161. My responses to questions in this section are primarily based on my review of documents and contemporaneous press reports and parliamentary reports. I would

also draw the Inquiry's attention to Chapter 10 of "The End of Innocence" [Exhibit WITN4500009] by Simon Garfield, which contains a lengthy retrospective interview with myself following the HIV compensation campaign.

Q65. When did the Haemophilia Society begin campaigning for compensation for haemophiliacs infected with HIV/AIDS as a result of contaminated blood products?

162. As I recall, formal political and media campaigning for direct financial support commenced in the summer of 1987, however the campaigns by the Society were always about more than financial compensation.

163. Over time a number of areas of need for the infected community developed. These included: improved, information, treatment, care and support for those affected; safer products to stop any further infections, particularly amongst children who may not have been treated with infected products; financial assistance for those affected and their families to help with the direct damage that deteriorating health and bereavement was causing; and compensation or recompense for the damage caused.

164. Representation to the Government and healthcare providers on issues such as safety of blood products, and care and support issues, started before the formal campaign, and had already commenced when I joined the Society in 1985.

Q66: What prompted the Society to begin campaigning for compensation for haemophiliacs infected with HIV/AIDS as a result of contaminated blood products[BAYP0000010_144; PRSE0007003]?

165. As other witnesses will have stated, the view of the prognosis for people with haemophilia and HIV was mixed before 1984. However, from 1984 onwards it became clear that the scale and impact of the failure of government policy on the haemophilia community would be catastrophic.

166. Deaths from HIV of people with haemophilia from infected blood products over the ten year period from 1981 -1991 was:

1981 1
1982 0
1983 1
1984 2
1985 13
1986 31
1987 40
1988 39
1989 54
1990 64
1991 72

167. The above figures are from Hansard Written Answers on 5 February 2004 and 19 December 2003 (screenshots are at Exhibits WITN45000010 and WITN45000011). The data shows the step change in 1984/5 in those becoming ill and dying, and this, together with the direct calls from impacted members to the Society, prompted the

Society to act to in the first instance call for help and support for those infected, ill and the bereaved.

168. In the period up to the formal launch of the political and media campaign in the summer of 1987, I recall that various discussions took place amongst members of the Executive Committee, supportive clinicians and politicians and members of the Society, about the nature of the campaign and what should be the campaign objectives.

169. It has always been the core rational for the campaign that it was a failure in policy and action by the Government and associated public bodies that was the direct cause of people with haemophilia being infected through blood products. The failure to achieve self-sufficiency as promised, together with failures in donor screening, resulted in thousands of infections and deaths. Accordingly, the Society sought to bring moral and public pressure on government to provide redress for those it had failed so badly.

170. On the matter of compensation, the Government was adamant that this should be a matter for the courts and the legal system. They repeatedly stated publicly and privately that individuals should take legal action for negligence and that the Government would not pay 'compensation'. I attach copies of two Parliamentary Written Answers [Exhibits WITN45000012 and WITN45000013] to this effect from January 1987 and April 1987. I am confident that the Inquiry will have many other references to this policy, from its own investigations of Parliamentary and Government papers. The Society was only too aware of the urgent need for financial assistance for those affected and also aware that action through the courts could take many years and even then, may not have been successful, when there was an urgent need for financial help immediately.

171. I also recall, although I do not specifically recall the source, that there had been internal DoH correspondence along the lines that, by forcing individuals to undertake lengthy legal actions, most would have died by the time the cases were concluded, thus reducing the cost to the Government.

172. Accordingly, it was decided that in the first instance, the political and media campaign would be focused on the immediate financial needs of those affected, whilst still very much believing that recompense for the failure of government policy that had been the cause of the issue, should still be pursued as and when possible. Please also see my responses to supplementary questions at paragraphs 347 - 356 below.

173. When the first phase of the campaign had some limited success with the granting of £10m and the establishment of the MFT, the Society moved on to a second phase of political and media campaigning for recompense, working in parallel with some of the legal actions that had been started. Please see my answer to Q 69 for further detail about the legal cases. Please also see my responses to supplementary questions at paragraphs 357 – 359 below.

Q67: Please identify who was responsible for determining the Society's position in relation to campaigning for compensation for haemophiliacs infected with HIV/AIDS as a result of contaminated blood products.

174. Ultimately, it was always the Executive Committee of the Society that agreed policy and positions and this was set out in, for example, Heamofact 13 and 15 [HCDO0000279_025] and [BAYP0000010_144]. The Executive Committee, was informed by a wide range of discussions within the wider Society membership, amongst the Trustees, and with political, legal and medical advice given on a personal basis i.e. outside the formal structure of the MAP.

Q68. What was your personal role in relation to the campaign for compensation for HIV/AIDS? [You may be assisted by HCDO0000279_025; HSOC0029476_071].

175. I was closely involved in discussions about strategy and tactics for the campaign, along with the Society's staff, particularly David Watters, key fellow trustees, particularly the Chairman the Rev Tanner, and our political and media advisors. I also helped draft and review campaign documents and media releases. I do not recall that I was involved in many direct meetings with ministers, government officials or MPs, these were normally undertaken by the Chairman, the Rev Tanner, and David Watters.

176. I acted on occasions as a spokesperson for the Society, both speaking on behalf of the Society, and as an individual who themselves had been infected with HIV. I recall doing TV interviews, as reported in Haemofact 13, as well as other TV, radio and press interviews over the years.

177. We pursued an intensive media campaign in advance of the meeting in Parliament in November 1987 and example of which is the attached Guardian article dated 29th June 1987 and Editorial in The Daily Telegraph of 17th October 1987 and a [Exhibits WITN45000014 and WITN45000015].

178. I took a prominent role in the launch meeting for the campaign on 5th November 1987, at which [HSOC0003459] set out the Society's case. This was widely reported in the press and particularly in the attached article that appeared on the cover of The Times on 6 November 1987 [Exhibit WITN45000016].

179. I am quoted in the piece as having "dwelt on the 'devastating' financial penalties of having contracted the virus. It was impossible to get life insurance and endowment mortgages to protect dependents. A high protein diet and extra heating were vital in warding off infection. Jobs were jeopardized."

180. I am quoted by Garfield as saying at the meeting "I do not believe that the government – if it is truly a caring government – will stand by while widows and orphans are thrown out of their homes."

181. Taking a high profile, as an individual with HIV in 1987, was not without its risks. The day that the Times article [WITN45000016] appeared with my photograph on the cover, I was admonished by a senior member of the executive team of the PR

consultancy I was working for, on the basis that clients would not want to work with someone with HIV. Fortunately, my clients and other colleagues were very supportive of my position.

182. Dr David Owen saw the article and he and I knew each other on a personal basis. Following the launch event I went to see Dr Owen to brief him on the campaign, given his role, when as Minister of Health, he had made the first commitment to self-sufficiency in January 1975. It was at this meeting with myself, that Dr Owen said that he would call for his ministerial papers relating to the issue of self-sufficiency, which subsequently he learnt had been destroyed, as recorded in his evidence to the Inquiry.

183. The effectiveness of the initial campaign in effecting a major U turn in government policy is illustrated by the Cabinet Committee paper [CABO0100001_002], written by the Secretary of State, and referenced in earlier evidence to the Inquiry which said, "the Society have successfully got across their view that the haemophiliacs' problems with AIDS is due to Government's failure to ensure self-sufficiency in blood products. Whilst unfair this is difficult to refute convincingly in presentational terms."

184. The Guardian article of 17 November 1987 [Exhibit WITN45000017] sets out an account of the political aspects of the campaign and the steps taken to achieve the Government's change in policy.

185. My role continued into the second phase of the campaign, following the granting of the initial £10m and the establishment of the MFT, where we focussed on compensation. This stage focussed on the moral imperative of the Government in providing recompense for the failure of government policy and formally continued until 1991, although we never accepted that the subsequent payments in 1989 and 1991 were in any way adequate compensation for the consequences of infection via blood products. See also my responses to supplementary questions at paragraphs 357 - 359.

Q69. What were the goals and priorities of the campaign for compensation for HIV/AIDS?

a. How were the goals set?

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

c. Were the Society's goals communicated to the Government? Was there a response?

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

e. Were these statements or assurances relied upon? If so, how?

186. There were three stages to the political and media campaign, the first stage was to gain immediate financial help for those most in need, the second was for financial

recompense in the form of lump sum payments, and the third stage was to regularly keep the pressure up for amounts of compensation that truly reflected the enormous damage caused by NHS treatment.

187. The first stage resulted in the establishment of the MacFarlane Trust in 1987, the second stage resulted, in partnership with the various legal cases, in the payments in 1989 and 1991, and the final stage continues to this day, and the Society has been regularly calling for a fair and just final settlement.

188. As I have said in my response to Q 65, the campaigns were always about more than compensation.

189. In addition to these elements of the campaign, the Society has tirelessly been working in making representations to government and others on issues such as treatment and care and the safety and availability of factor products.

HIV Litigation

190. For context, I give an account of the role of the Society in relation to the litigation claims for HIV that were taking place.

191. The Society was not itself a party to litigation and I believe had been advised against seeking to become a party. It did however support and assist the litigation efforts by publicising the issues around litigation on a consistent basis in Society publications and referring any individuals to Solicitors working on cases and also supplied any documentation that might have been of assistance.

192. The Society undertook a continuing political and media campaign from 1987 to 1991 in parallel with the litigation process. The Society kept raising the issue of the strong moral case for no-fault compensation payments through parliament, with ministers and in the media. A high profile press campaign, particularly supported by the Sunday Times and the Guardian, ensured that public and political pressure was kept on the Government to agree to a settlement. [See exhibits WITN45000014, WITN45000015, WITN45000016, WITN45000017, WITN45000018 and WITN45000019].

193. On the political front the campaign continued, particularly encouraging members to contact their own MP. I attach examples of the letters sent to members in October 1989 and November 1990 [See Exhibits WITN45000020 and WITN45000021]. The two reports in the Bulletin no3 1990 [Exhibit WITN4500008 and Exhibit WITN45000022] give good and detailed accounts of the HIV campaign for compensation at this time.

194. Towards the end of 1990, as Garfield reports in Chapter 10 of his book, "The Haemophilia Society placed a series of startling large-scale advertisements in the national press. These featured a young boy's face overprinted with the text, 'Heredity gave him haemophilia. Then the NHS gave him HIV' "

195. I believe that there is no doubt that the public and political pressure generated by the Society's campaigns, were critical to the Government deciding to make additional payments in 1989 and 1991.

196. In relation to question (a) of how goals were set, see answer to Q67 above.

197. As to question (b) on the extent to which the Haemophilia Society achieve these goals during my tenure, the answer is partially, however a full and fair settlement was not, and has not, been achieved to this day.

198. In response to question (c) whether the Society's goals communicated to the Government and was there a response, there were regular and repeated meetings with officials and ministers over the period from 1986 to 1991

199. The consistent response from Government up until November 1987, as evidenced in repeated ministerial statements, was that "compensation was a matter for the courts". This only changed with the announcement of the grant of £10m to establish the MacFarlane Trust in November 1987. The "compensation was a matter for the courts" response was again in use by the Government until the first lump sum payment in 1989 and again until the second lump sum payments in 1991. An article from the Guardian of 17th November 1987 sums up how effective the initial campaign had been for such a small organisation [WITN45000017].

200. In relation to question (d) I do not recall any statements and assurances were made by the Government to the Society, other than any ministerial statements or DoH press releases made relating to the payments in 1987, 1989 and 1990.

201. In response to question (e) given the failure of the Government on so many fronts over many years, starting with the non-provision of self-sufficiency, through the stonewalling and obfuscation in relation to compensation and financial support for those affected, the Society placed no reliance on any statement made by the Government at any time.

Q70. 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?

202. First, I believe it would be incorrect to draw a distinction between 'The Haemophilia Society' and the Haemophilia Society membership. The Executive Committee (Trustees) were elected annually by the membership at the Society AGM.

203. Society Members not only had opportunities to inform the campaign, but they were also essential elements of that campaign. The Society held a series of regular open member meetings each year, including the AGM, Council Meetings where local groups were represented at least twice a year, an annual members' conference, together with ad hoc seminars and other meetings. In addition, many members were not shy in making their views known to the Chairman and Trustees.

204. The Society recognised that there were some amongst the membership, who wanted an even more aggressive and emotive campaign, whilst others were concerned about the impact the campaign would have on them and their families, in terms of stigma and association with HIV and worried about the level of publicity the campaigns generated. Striking this balance was a constant challenge for the Trustees.

205. This issue was raised in The Bulletin 1989 No 1. Exhibit WITN45000023] in an article "Finding a balance". This article states:

> "The Editorial Board has recently been considering the extent to which matters relating to HIV and AIDS should feature in the Bulletin and Update. Some readers have suggested that these topics receive too much attention in these pages."
>
> "Since the advent of AIDS, the Haemophilia Society as a whole has made strenuous efforts to maintain a 'One Society' approach for people with haemophilia – with and without HIV. This policy has been adopted in the belief that it is haemophilia itself which is the cause of common concern and fellow-feeling."

206. I believe that this approach was totally correct and guided the activities of the Society throughout this period, including when the impact of HCV became apparent. I entirely understand that there are individuals and groups that believe that the Society should have done more for people with HIV and /or HCV, however as Trustees we had a duty to the community as a whole, whilst continuing to make strenuous efforts to secure justice for those affected.

Q71. What was the Haemophilia Society's position (if any) with regards to compensation for haemophiliacs who were infected with HIV/AIDS as a result of contaminated blood products during your tenure? If this changed over time, please detail when and why.

a. Was this communicated to the Government? Was there a response and if so what was it?

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

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

207. See my answers above and my response to Q 69 in particular.

5.2 Campaign for Compensation for Hepatitis C

208. I recall much less about the HCV compensation campaign, in part because I left the Executive Committee in 1996 due to failing health caused by my HIV and development of AIDS. As the Inquiry may be aware, an aspect of AIDS was a degree

of mental impairment, sometimes known as 'brain fog', I suffered from this and my memory of all events around this period is poor.

209. When I returned in 1998, I became Treasurer and was more involved in the administrative side of the Society's activities than the campaigning aspects.

Q72. In 1994, the Services Committee considered a proposal by the Hepatitis Committee for a HCV publicity campaign " whose objective it would be to gain better treatment and care for those infected and financial help from the Government as and when those infected became ill " [HSOC0023353]. You expressed the view that " A high profile campaign was not yet appropriate." Several other members of the Committee also disagreed with the proposal on the basis of the publicity that would result from such a campaign. Please explain why you considered that a high profile campaign was not yet appropriate. Why was the Haemophilia Society concerned with the publicity that would come from a Hepatitis C Campaign?

210. The concerns expressed in my response at paragraph 101 – 102 above from 1991, still held in 1994, and it was not felt at the time, that knowledge of the risks of HCV had changed substantially over the period.

211. The minute outlines the concerns the Committee had about a high profile campaign at the time. Mr Colthorpe's remark 'that in the public eye hepatitis would take on the same dimension as HIV" was a very real concern for many members of the Society. Dr Mark Winter, a highly regarded haemophilia physician, raised the point about there "being insufficient knowledge" and also "that increasing public awareness creates a risk of causing panic and discrimination."

Q73. When did the Haemophilia Society begin campaigning for compensation for haemophiliacs infected with HCV as a result of contaminated blood products?

212. I do not recall, however a document has come to my attention [Minutes of Services Committee 12 April 1995] [Exhibit WITN45000024] that sheds light on this and sets out the nature of the campaign and its launch. This document states:

> "That the campaign had been officially launched on 14th March 1995, the day before a debate in the House of Lords on a motion put forward by Lord Ashley. The launch had been covered by the BBC TV News, some radio stations and some local papers, but not the national papers. The basis of the campaign would be that because of the many similarities with the HIV infection the Society was of the view that there should be more equitable treatment between those infected with HIV and those infected with HCV.
>
> "The Society was calling for:
> i) an across the board ex-gratia payment to all those infected with HCV through contaminated blood products.
> ii) access to a hardship fund for those who became ill and the dependents of those who die.
> iii) as a matter of urgency, payments to those who are already ill and the dependents of those who have died."

"In addition, the Society would be calling for adequate resources for haemophilia centres and for research, and for a public education programme."

213. The minute continues "The press release was sent to over 500 MPs and an all party meeting would be held in the Commons on Wednesday 26th April. Graham Barker also reported that the response from MPs to the letter from the Society had been a good one, and that over 100 had given indication of support, and 150 letters had been sent to the Secretary of State on the matter. As well as this, members who had written to their MPs had also been responded to positively."

Q74. What prompted the Society to begin campaigning for compensation for haemophiliacs infected with HCV/HCV as a result of contaminated blood products [BAYP0000010_144; PRSE0007003]?

214. I do not recall. It could have been as a result of an increase in more severe clinical presentations caused by HCV, but that is speculation.

Q75. Please identify who was responsible for determining the Society's position in relation to campaigning for compensation for haemophiliacs infected with HCV/Hepatitis C as a result of contaminated blood products.

215. I do not recall specifically however I assume it was ultimately the Executive Committee as with all policy issues.

Q76. What was your personal role in relation to the campaign for compensation for haemophiliacs infected with HCV as a result of contaminated blood products? [You may be assisted by HSOC0003794]

216. I do not recall other than as referenced in previous questions relating to Hepatitis. As previously, I believe I would have given advice on the political and media aspects of the campaign, but I do not recall specifics. I was absent from the Board for a number years and when I returned it was in a very different role. I have a broad recollection that the Board employed external lobbying advisors to conduct much of the campaign but do not recall specifics.

Q77. 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?

c. Were the Society's goals communicated to the Government? Was there a response?

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

e. Were these statements or assurances relied upon? If so, how?

217. In relation to (a) – (e), I do not recall in detail, other than to refer to my answer to question 73 above. I recall that the Society gave evidence to the House of Commons Health Select Committee in about 1999, which may further assist the Inquiry, however I do not possess a copy of the evidence or recall any details.

Q78. 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?

218. My answer to Q70 paragraphs 202- 203 above, would have also applied to the Hepatitis C compensation campaign.

Q79. What was the Haemophilia Society's position (if any) with regards to compensation for haemophiliacs who were infected with hepatitis as a result of contaminated blood products during your tenure? If this changed over time, please detail when and why.

a. Was this communicated to the Government? Was there a response and if so what was it?

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

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

219. In relation to (a) – (b), I do not recall other than answers to question 73. In response to (c), I would reiterate my view that throughout my tenure at the Society, given the failure of the Government on so many fronts over many years, starting with the non-provision of self-sufficiency, through the stonewalling and obfuscation in relation to compensation and financial support for those affected, the Society placed no reliance on any statement made by the Government at any time.

Q80. In a meeting of the Hepatitis Task Group dated 11 January 1995 [HSOC0003794], Graham Barker reported that the two of you had " met with Tom Kelly at the Department of Health to outline the Society's objectives of gaining financial help for individuals infected, increased resources for treatment and care, more research and better public education ." What did you tell Tom Kelly? What was his response? Were any assurances given? If so please set them out. If not, what was the outcome of this meeting? Was any written confirmation of the meeting provided? If so please provide a copy.

220. I do not recall the meeting and do not possess any notes relating to it.

Q81. You wrote a letter to Chris Hodgson dated 26 September 2000 [HSOC0000365], where you stated that as treasurer, you " cannot support the political campaign for financial assistance for those affected by HCV' '. Why were you unable to support the political campaign? Was this a matter of your personal belief or did it arise from your role as treasurer? If the latter, please explain why.

221. This letter was written, as is stated in the opening line, "in my capacity as the Society's Treasurer". I went on to say "I have a responsibility to the Board and to the

Society to safeguard the Society's assets, and to warn the Board of the financial implications of its actions."

222. I had a legal and fiduciary duty to put the interests of the Society, and the safeguarding of its assets, above my personal beliefs and wishes, and I recall that at the time the Society was operating a deficit budget.

223. My personal belief, not least as an individual coinfected with HCV, has always been that those contaminated with HCV should be treated on a fair and equitable basis to those contaminated with HIV.

224. My recollection was that after five years of campaigning, there had been little substantive progress and that the Government had been firm and consistent in refusing to extend help to those infected with HCV. According to documents made available to me, the campaign was reviewed at a meeting on the 11th September 1990. [Exhibit WITN45000025] Following this meeting, this letter, seeking legal advice, was written to ensure we had a sound legal basis for continuing to expend Society funds and resources on the Hepatitis C campaign, when the evidence at the time was that the campaign was not going anywhere.

225. The letter sets out at length the concerns that I, most of the Trustee Board, and indeed the Chief Executive, had about the legal basis for the campaign. Of note is Karin Pappenheim's comment in the covering letter to Paisners "I believe his points are well founded".

226. The letter should also be seen in the context of a very public debate at the time relating to Charities conducting "political" campaigns, as well as a degree of trustee training we had received, making clear our personal liabilities for safeguarding the charities' assets.

227. The letter actually turned out to be helpful in achieving progress in the campaign as, based on the advice from Paisners, as recorded in the Minutes of 30th November 2000 [Exhibit WITN45000026], the Society moved forward to employ a professional lobbying company to take over and conduct the campaign at an estimated cost of £115k for the first year, a selection process I led. Minutes of the meeting of 19th January 2001 and 28th February 2001 refer [Exhibit WITN45000027 and [WITN4500028]. I do not recall any more than what is set out in the documentation.

5.3 Self-Sufficiency

Q82. Please identify who was responsible for determining the Society's position in relation to self-sufficiency.

228. All policy decisions were agreed by the Executive Committee.

Q83. How and when was the Society's position regarding self-sufficiency communicated to the Government? If this changed over time, please detail when and why.

229. I cannot recall details, but David Watters and Graham Barker were always the primary points of contact with Government departments.

Q84. 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?

230. a. Prior to my time on the Executive Committee, my understanding is that from the initial commitment by Dr Owen, as Minister for Health, in 1975 to self-sufficiency onwards, the Government regularly made such commitments through private communication with the Society and in ministerial and public statements. A search of Hansard would I am sure provide many examples. Similar commitments were regularly made also once I had joined the Committee.

b. I do not recall that they did.

c. No it did not. The Society hoped that one of the many commitments might actually happen one day, but it had been let down so many times over a more than ten year period that such commitments carried little credibility with the Society.

d. The Society had no way of verifying ministerial promises.

e. The Bulletin would have regularly contained information on any statements by ministers or the Department of Health.

5.4 Reduction of Risk of Blood Products

Q85. Please identify who was responsible for determining the Society's position in regard to reducing the risk of blood products during your tenure?

231. All policy decisions were agreed by the Executive Committee.

Q86. What were the key issues that the Society pursued?

232. As I recall, issues included, but were not confined to: Donor screening; product testing; viral inactivation, including heat treatment, detergent and monoclonal techniques; use of 'high purity' products; and in due course the use of recombinant products.

233. The issues the Society were most concerned about, depended on the state of knowledge at the time, and also as new products and processes were developed.

Q87. How, when and with whom, was the Society's position relating to reducing the risk of blood products communicated to the Government? If this changed over time, please detail when and why.

234. I cannot recall specifics, but there was a regular and continuing dialogue with Government officials over these issues, which would have been undertaken by Mr Watters and Mr Barker on behalf of the Society. We also sought to influence third parties such as journalists and MPs to bring pressure to bear on government as I have described in detail in my preceding answers. Also see my response to Question 89 below.

Q88. 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.

235. I cannot recall any assurances on this issue and have described in previous responses the government's position generally to the best of my recollection. See also my responses to Question 89 and 90 below.

Q89. What decisions and actions were taken by the Society based on information provided by the Government (for example, via heat-treatment and screening of blood donors) during your tenure? If this changed over time, please detail when and why.

236. As I recall, the Society's view on these issues would have been based on a variety of sources, not just any information from the Government, but also information gained from clinicians, other national haemophilia societies and the WFH and other sources if available.

237. Based on these views, the Society consistently pressed for the widespread use of what was believed to be the safest possible products at the time, independently from any government position. Clearly the view of what were the "safest possible products" developed over time and thus the Society's position changed to reflect current knowledge.

Q90. Did the Haemophilia Society rely on assurances by the Government or individuals in public office on the safety of blood products? If so, please provide details, identifying how the Society's approach changed because of those assurances.

238. No – we had little or no confidence in any Government statements or assurances, given the consistent failure of successive governments to implement policies that would have saved hundreds, if not thousands, of lives.

239. Answer to question Q 89 also applies.

5.5 The Supply of Imported Blood Products

Q91. 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.

240. All policy decisions were ultimately agreed by the Executive Committee.

Q92. Were you involved in lobbying against the ban of imported blood products? If so, what involvement did you have?

241. My comments below relate to the period subsequent to 1985 when I joined the Executive Committee.

242. I was not involved. During my tenure from 1985 onwards, David Watters and Graham Barker were always the primary points of contact with Government departments and would have been responsible for making our positions known to relevant bodies.

Q93. 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.

243. My responses relate only to the period from 1985 when I joined the Executive Committee.

244. As I recall, the Society was very concerned to both maintain levels of haemophilia treatment, i.e. the use of factor concentrates to treat bleeding episodes and provide cover for interventions such as surgery, whilst at the same time seeking to ensure that this was done with the safest possible products.

245. From 1985 onwards, it became clear that heat treated products were probably the safest option available and that these were primarily available from overseas, as I believe BPL did not have the capacity to manufacture sufficient quantities of heat treated factor. Accordingly the Society was very concerned about any proposals to ban the use of imported products, which were potentially safer than domestically produced products, and any such ban at the time was likely to cause a drop in the levels of products available for treatment, leading to potentially dangerous health implications for patients through restrictions on the use of factor products.

246. Further, any possible threat that treatment would have to revert from the use of factor products, back to cryoprecipitate, due to shortages in the availability of factor concentrates, would have been unacceptable to the haemophilia community in terms of the quality of care and quality of life. I also believe that there was a serious shortage of cryoprecipitate, as plasma was being diverted to BPL for production into factor concentrates.

247. It is important to recall, as has been pointed out in previous evidence to the Inquiry, that Cryoprecipitate had significant disadvantages over the use of factor concentrates. Speaking as a patient, it was not practicable for home treatment, it caused severe and unpleasant reactions, and it would have had a devastating impact on quality of life.

248. There was also, I understand, a strong suspicion that proposals to ban imported heat treated products, was driven by commercial pressures to protect BPL's share of the market.

Q94. 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.

249. I do not recall.

Q95. How, when and with whom, was the Society's position relating to reducing the risk of blood products communicated to the Government? If this changed over time, please detail when and why.

250. As above, David Watters and Graham Barker were always the primary points of contact with Government departments and would have been responsible for making our positions known to relevant bodies.

Q96. 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.

251. I do not recall.

Q97. Did the Haemophilia Society rely on assurances by the Government or individuals in public office on the safety of blood products? If so, please provide details, identifying how the Society's approach changed because of those assurances.

252. No – the Society tended to view any and all assurances from the Government with a high degree of scepticism based on previous experiences over many years. In particular the failure of government policy on self-sufficiency, that if it had been implemented by successive governments, would probably have led to a vastly reduced number of infections through the use of blood products. See also my answers to Q 90 and Q 89.

5.6 European Self-Sufficiency

Q98. In a meeting of the Executive Committee dated 4 October 1991 [HSOC0010387], you reported that the European Commission had issued a Directive maintaining that blood products "should be sourced from volunteers within European countries; at present they came from the US and paid donors since Europe was not currently self sufficient in blood products as there were not enough donors or fractionation facilities. Full implementation of the Directive could put at risk the supply of blood products and standards of care, unless the Society was vigilant....The European Commission had done a survey of member states, and was due to publish a paper towards the end of the year and the Society should be ready to respond. A pan-European paper, whose position had not been quite as strong as that of the Society's, had been submitted on behalf of the European Consortium." Please explain:

a. Where did you obtain the information from, that you reported to the Executive Committee?

b. Had you discussed the issue with any medical or fractionation experts before making this statement? If so, please set out who you spoke to, when and what they said.

c. Why did you think that full implementation of the Directive put the supply of blood products and standards of care at risk?

d. On what basis did you state that there were insufficient donors?

e. What was the position that the Society had taken?

f. What was the position taken in the pan-European paper? Why was it not as "strong" as the Society's position?

253. a. I do not recall specifically, however the European Haemophilia Consortium monitored policy developments within the European Commission, as did Mr Watters and Mr Barker, so these were the likely sources of information.

b. I would not have done so, as I believe I would have been reporting on the situation as understood from the EHC and Mr Watters and Mr Barker.

c. As I recall, the proposal was a European wide application of the issues outlined in answer to question no. 93 above. I believe that the draft Directive was based on a report by Prof Van Aken. The proposal was that factors should only be used that had been sourced from voluntary unpaid plasma donations within the EU. The Van Aken Report indicated that there was insufficient domestically produced factor concentrates within the EU to maintain current levels of haemophilia treatment. The report proposed in response to this shortage, that there was 'excessive use' of factor products, a concept I was to later publicly describe as "morally repugnant" [HSOC0000671] page 18.

I do not possess any of these EU documents, however I am confident that they will be in the public domain.

Accordingly, the Society believed that the restriction of imports, which was the implication of the proposals, would lead to a severe deterioration in the health and wellbeing of people with haemophilia across the EU. The report of the meeting [HSOC0000671] covers the issues comprehensively.

I also recall understanding, that many EU countries were concerned that the widespread use of imported products would undermine the viability of their domestic blood transfusion and plasma processing capability. Accordingly, there were strong commercial pressures for restricting imports from outside the EU by using such barriers.

d. I believe that this was stated within the Commission report. In addition, this fact is later referenced extensively in [HSOC0000671], the report on the conference held on 23rd April 1993 in Brussels,

e. As I recall, the Society took the position that patients should have access to sufficient blood products to maintain and improve their health and quality of life, and that these products should meet the highest possible safety standards.

From the 1990s onwards, I recall that it was the Society's view, and that of most treating physicians, that the safety standards of imported blood products met, and frequently exceeded, those of domestically produced products therefore there were no safety grounds for banning importation.

f. I do not recall in detail and do not possess a copy of the paper. Some haemophilia national organisations in Europe had a stronger philosophical commitment to the use of voluntary unpaid donation and were of the view that this took priority over access to adequate quantities of factor for treatment. The Society did not believe that these two priorities were mutually exclusive, however in order to be able to table a united paper, a consensus position would have been agreed within the EHC.

Q99. In a meeting of the Executive Committee dated 4 February 1993 [HSOC0024825], it is reported that you, Mr Watters, Mr Barker were working on a response to the Van Ekan report on self-sufficiency within the EU. What was the report about? Why were you selected to work on it? From where did you obtain your information? Please provide a copy of the Society's response if it is available.

254. The report was the Van Aken report and proposal, as outlined in answer to question no.98 above and the same issues and concerns remained. I was involved as I had taken a close interest in the topic over a number of years. As above, the European Haemophilia Consortium monitored policy developments within the European Commission, as did Mr Watters and Mr Barker, so these were the likely sources of information. I do not possess a copy of the response.

Q100. In a meeting of the Executive Committee dated 23 March 1993 [HSOC0024826]:

a. You and Mr Milne " raised dissenting voices that not enough time was given to consideration of topics such as recombinant products, high purity blood products and European matters. " Why did you consider that insufficient time was given for these topics? What should have been discussed that was not? What was the outcome of your raising "dissenting voices"?

b. The Society " felt that caution should be exercised in the way the Society accepted and made use of funds from commercial sources, while accepting Mr Taylor's point that the Society would not have been able to be influential in Europe had it not received sponsorship. " Please expand on this. In what way were the Society influential in Europe? What funding had been provided to enable this, from whom, how much and when? Had that funding been provided with any requirements on you about what you said or the influence you sought in Europe.

c. " The Committee noted the Society's recent activities in Europe, including the lobbying over the Ceci Report, effectively emasculating it." What was the Ceci Report? What position did the Society take in relation to it? Why did the Society lobby over it? How did the Society successfully "effectively emasculate" it?

d. " Mr Watters reported that the World Federation of Hemophilia was sponsoring a conference in Brussels on Friday April 23 at which he and Mr Taylor had been invited to participate. " Why were you selected to participate? What was the conference about?

255. a. I do not recall in detail, but a close reading of the minute indicates that we believed that time should have been devoted on the agenda at the forthcoming Executive Committee 'away day' to discuss these issues. The minute goes on to suggest that these were topics that would be regularly discussed within the regular structure of committee and Executive Committee meetings.

b. As outlined previously, the Society worked through the EHC, and also Mr Watters and Mr Barker, in making representations on European matters to relevant bodies on matters of concern to the Society and its members. The minute details funding received, which I believe was used to fund travel expenses and the costs of meetings. I do not believe that any conditions were placed in the funding as to regards what we would say.

c. The Ceci report was, I believe, a further iteration of the Van Aken Report and draft Directive from the European Commission, covering the same issues and with the same concerns by the Society relating to the access to sufficient blood products to maintain and improve their health and quality of life, and that these products should meet the highest possible safety standards. I do not recall any specifics as to its emasculation.

d. The conference was "The EC Single Market in Plasma Products: A Question of Circulation" referred to in Question 101 below. The conference brought together a wide range of individuals from across Europe representing the pharmaceutical companies involved in blood factor production, the government agencies, such as BPL, that produced blood products, leading haemophilia physicians including Prof Mannucci from Italy, considered a world authority on haemophilia, and representatives of patient groups from across Europe. It debated the proposals being brought forward by the Van Aken and Ceci reports and their proposals to limit the use of plasma derived products in haemophilia care. I was invited as I had taken an interest in the topic over a number of years and accordingly had some knowledge of the issues concerned and was thought to be a good advocate from the patient community.

Q101. In the Executive Summary of the The EC Single Market in Plasma Products: A Question of Circulation Forum, held in Brussels on 23 April 1993 [HSOC0000671], you stated that " Regulation is absolutely critical to preserve safety for blood products, but the Commission should not encourage the Member States to put up artificial barriers which would deny people with haemophilia access to the products which have transformed (and) improved their lives" . What did you mean by " artificial barriers" ? Were any of the barriers you were concerned with, addressing safety matters? If so, what were they and why was access to the products more important than their safety? Why did you consider that there was a risk of barriers denying people access to the products?

256. I consider the full report of the meeting an excellent and accurate account of the issues surrounding European self-sufficiency. I believe that the account of my

contribution on page 18 of [HSOC0000671] is wholly accurate, and comprehensively sets out the concerns of the haemophilia community at the time. I believed that restricting factor use, to only that derived from voluntary unpaid donations, was an artificial barrier, and I stated that the suggestion in The Van Aken report that there was excessive use of factor products in the treating of haemophilia as "morally repugnant".

257. I would also endorse in particular the comments in the full report by Rev Alan Tanner, Prof Pier Mannucci, and Brian O'Mahony.

Section 6: Litigation

Q102. What role did the Society play in the Hepatitis C litigation?

a. Please include consideration of [HCDO0000015_015] . Why was this document prepared? Who wrote it? When did they write it? Who was it provided to? How was the advice contained in this document formulated? Were any external experts used to write the content of this document? If so, please set out who that was, what their advice was and what they were told in preparing that advice.

b. Please consider David Watters' report to the Haemophilia Centre Directors' Annual Meeting 1993, dated 29 September 1993, under the heading Hepatitis, where Mr. Watters refers to the Society's "line" on compensation [BART0000879_001].

i.Why, when, and on what basis, did the Society decide " to advise people of the unlikely nature of any claim for medical negligence succeeding "?

ii. Why, when, and on what basis did the Society decide that there would be " no public profile campaign, certainly based on present knowledge and experience?"

c. In the same report [BART0000879_001] David Watters' wrote that "1993 has been a difficult year for the Society. " Why had 1993 been a difficult year?

258. My recollection was that a number of firms of solicitors had been gathering individual claimants to bring cases. I believe that the Society had also taken legal advice on the prospects and issues relating to litigation. I also recall that the legal advice received by the Society, and that being put forward by the various legal firms, was in many cases contradictory.

259. The Society decided that the best thing it could do was to a) give general advice on the prospects for litigation as was broadly agreed by the various legal opinions received b) give members the names of lawyers involved, without giving any particular recommendations and c) to assist any cases by the provision of papers or information held by the Society.

a. The "Hepatitis C Infection - Medical Negligence Claims" document [HCDO0000015_015] was written to meet the needs outlined above. It states that it was written by David Watters on the 28th September 1993 and was made available to anyone who requested information on potential litigation. I do not know the basis of the advice, but I believe the advice was formulated based on the legal advice received from lawyers conducting cases.

b. ii. I cannot say specifically, however referring to [HSCO0000015_15] it was believed that the vast majority of individuals infected with HCV had Severe Haemophilia and were likely to have been infected prior to 1985 when safer products became more widely available.

ii. I do not recall.

c. I do not know and cannot speculate why Mr Watters said that.

Q103. What role did the Haemophilia Society play in seeking a public inquiry? When did the Haemophilia Society consider an inquiry was a possible course of action? Why was that decision made then? Please set out chronologically the Society's campaign and or involvement in the campaign for an inquiry, including any discussions with the Government and any assurances that were received from the Government.

260. I do not recall, however the Trustee minutes of 19th January 2001 [Exhibit WITN45000028] reference a public Inquiry as being an objective of the campaign at that time, I have no recollection as to if a Public Inquiry had been sought prior to this.

Section 7: Interaction with Trusts and Schemes

Q104. Please describe your involvement with and/or recollection of the circumstances in which the Macfarlane Trust was established.

261. The Macfarlane Trust (MFT) was established to administer the £10m grant made by the Government in November 1987 to provide financial assistance to people with haemophilia who had been infected through contaminated blood products, and their dependents.

262. The Government stipulated that a new trust was to be set up to administer the funds.

263. I, and the Society as a whole, considered the sum provided as totally inadequate, however in the face of the urgent need of many of our members, we described it as "a start" and made it clear that we would continue to press for a fuller and more comprehensive financial settlement.

264. I was not directly involved in establishing the Trust, however I recall that the Society were content to have an independent body established for a number of reasons.

265. Confidentiality was a top concern, and it was believed that those applying for assistance might have more confidence in an organisation dedicated to that purpose, rather than a busy office dealing with a wide variety of other issues and people.

266. Secondly, the Society was already greatly overstretched in terms of pressure on its staff and administration and it was felt that it could not manage the administration of the fund as well.

267. Finally, it was important that the funds were kept separate from those of the Society, particularly in connection with fundraising. I recall that there was a misunderstanding by some potential donors to the Society that it had been the Society that had received the money, and therefore it was no longer in need of financial support. Nothing could have been further from the truth.

Q105. What did you understand the aims and objectives of the Macfarlane Trust to be? What principles or philosophy underpinned its establishment?

268. These are set out in the Annual Reports of the MFT [MACF0000045_003] and [MACF0000045_29] "The objects of the Trust are to relieve those persons suffering from haemophilia who as a result of receiving infected blood products in the United Kingdom are suffering from Acquired Immune Deficiency Syndrome or are infected with human immunodeficiency virus and are in need of assistance, or the needy spouse, parents, children and other dependents of such persons, and the needy spouses, parents, children or other dependents of such persons who have died."

269. My understanding was that the primary purpose of the Trust was to provide financial help to those most in need on a basis of individual need and circumstances.

Q106. What involvement (to your knowledge) did the Department of Health or any other Government department have in the setting up of the Macfarlane Trust? In answering this question please address the following matters:

a. Were you involved in any consultation by the Department of Health or any other Government department about the establishment of the Macfarlane Trust, its functions, aims and objectives?

b. If so, please describe that process and set out the contribution you made to the consultation.

c. Was there any discussion as to why the Government chose to distribute monies via the AHOs rather than directly? What, if anything, were said to be the risks and benefits of this scheme?

d. Was there any discussion as to why the Government chose to exclude those who contracted HBV from the scheme?

270. My understanding was that the Department of Health was closely involved and consulted in the establishment of the Trust. I believe that David Watters, working with the Chairman Rev Tanner worked with the DoH in the establishment of the Trust.

a. No, I was not personally involved.
b. None, as above.
c. I was not involved, but I set out above my understanding of the view of the Society at the time in response to Q 104 above.
d. I was not involved in any of the discussions relating to the establishment of the Trust therefore am unable to answer.

Q107. The Inquiry are aware that you were a Trustee to the Macfarlane Trust from its inception [MACF0000002_002].

a. Please confirm your role at this Macfarlane Trustees meeting and any other(s) you attended.

b. The Inquiry notes that you were absent from a number of board meetings. Were you given an opportunity to provide your views as to the decisions being made during such meetings? If not, what if anything could you do if a decision was made that you disagreed with? Please give any examples of when this happened.

c. Please explain how you came to be appointed as a trustee and for what period. [You may be assisted by MACF0000045_030 and MACF0000045_029].

d. What induction, training and information did you receive from the Macfarlane Trust as to its functions, aims and objectives?

e. How much time did you devote to being a trustee of the Macfarlane Trust?
Please describe how your time was generally spent when discharging your role as trustee.

271. I can confirm I was a Trustee from inception in March 1988 until I believe February 1990, when it was clear that my work commitments did not allow me to take a full part in the workings of the Trust and I resigned in order to allow the Society to appoint another individual.

a. I had no specific role, I saw my role as a Trustee, along with the other trustees, to oversee the functioning of the Trust and to provide input on matters of policy as appropriate.

b. If I was unable to attend a meeting due to work commitments, I would have received papers and minutes of meetings and if anything was on the agenda, or had been raised in the minutes, that I felt strongly about, I would have raised this with the Chairman before the meeting.

I do not recall any examples where I dissented from a decision made at a meeting I could not attend.

I had a high degree of confidence and trust in the other trustees, particularly those nominated by the Society, most of whom I had known and worked with for some years. I knew that they would have had a very similar perspective to my own and would mirror any concerns or points of view that I would have had.

c. I cannot recall specifically how I came to be appointed a Trustee by the Society, probably because I had taken an active role in the campaign and had a good knowledge of the subject matter. In addition, I was an individual infected with HIV and so a potential user of the Trust. As noted above, I was trustee from March 1988 until February 1990 when I resigned due to pressure of work.

d. None specifically that I can recall, however since the Trust was newly established, we were familiar with the aims and objectives and were instrumental in establishing its initial policies and procedures.

e. As above, I would attend as many meetings as possible, however this was sometimes limited by my work commitments. I would review the papers and give my

views at meetings as required. I was not able, as some other trustees did, to go on visits around the country.

7.1 Appointment of Trustees

Q108. Please provide a description of the appointment process for trustees of the Macfarlane Trust and the composition of the board.

272. As set out in the MFT Annual Reports, "There are ten Trustees, four appointed by the Secretary of State for Health and six appointed by the Haemophilia Society. Trustees hold office for two years but are eligible for reappointment."

"One of the Trustees appointed by the Department of Health will always be a Haemophilia Centre Director and one a Haemophilia Centre Social Worker."

273. I do not know how the Department of Health chose its Trustees, I recall that the Society's nominees were chosen by, and approved by, the Executive Committee of the Society.

Q109. What was the process for electing/re-electing trustees at the Macfarlane Trust? In particular, what involvement did (a) the Department of Health (or any other Government department) and (b) any other organisation or person have in this process? Did these matters change over time?

274. Please see my response above. I recall that the Executive Committee of the Society continued to appoint trustees subsequent to my leaving the MFT however to the best of my knowledge the DoH or any other Government department had no involvement of the Society nominated trustees.

Q110. How, if at all, were positions advertised?

275. The initial trustees were not advertised, as there was need for urgent action to get the Trust up and running and paying out money to those in need as quickly as possible. I believe that it is possible that in later years, after I left, that the Society may have advertised for Trustees, but I do not recall specifically.

Q111. How many trustees were appointed by the Government, how many by the Haemophilia Society and how many were 'user' trustees during your tenure at the relevant AHO?

276. See my answer to question Q 108 above regarding overall composition of the Board.

277. I believe that the initial composition of the Trustee Board had a good and broad representation of the user community. I believe that the Chairman Rev Tanner's GRO-A GRO-A Peter Steven's GRO-A GRO-A after the Trust was established, Clive Knight GRO-A GRO-A I had haemophilia and HIV and have been fortunate to survive, Norma Guy GRO-A and was an active

member of the 'grassroots' of the Society and both Dr Jones and Christine Leitch had constant day to day contact with infected individuals through their work.

278. Towards the end of my tenure at MFT, I recall that there arose a concern as to whether a Trustee could also be a beneficiary of the Trust. I do not recall how this was resolved and this may have had an influence on the appointment of future trustees.

Q112. Were trustees remunerated for their work? Please include details of any policies on this, including policies for allowances/expenses.

279. No, the Trustees were not remunerated for their work, however they could claim reasonable travel expenses incurred, however I do not have any records of the travel policy. I never claimed any expenses in connection with my trusteeship.

Q113. What in your view, were the advantages and disadvantages to the Haemophilia Society and the Macfarlane Trust in you having a role with both organisations? In particular, did you consider you were conflicted at the board meeting on 22 June 1989 [MACF0000002_016] when the Haemophilia Society advocated for a rise in payments to beneficiaries?

280. As with the other Haemophilia Society Trustees, I believed that it was helpful in that we were regularly in communication with the broader haemophilia community and in the case of a number of us, were living with HIV. I do not believe it was particularly disadvantageous in any way during the time I was a Trustee.

281. With regard to the call for an increase in payments, I do not consider that I was conflicted. As a Trustee Board we debated issues and factors that the Society would not have taken into account in their request, such as the need at the time, to balance the desire to be generous, with the need to preserve the capital of the fund. I believe that the Society, if faced with the same issues as the trustees, would probably have come to a similar conclusion.

7.2 Relationship with Government

Q114. To what extent was the Macfarlane Trust independent from Government? How much oversight did the Department of Health (or any other Government department) have over it? In particular, did the Department of Health have any involvement with and/or give any direction/guidance to the Macfarlane Trust (and if so, what?) as to:

a. the composition of the board.

b. the content of any policies adopted by the Macfarlane Trust;

c. how the Macfarlane Trust should discharge its responsibilities to the beneficiaries;

d. the kinds of applications the Macfarlane Trust should grant; and/or

e. the quantum of the grants/payments it should make?

282. The MFT was independent of the Government, however the MFT was mindful to ensure that the Government was content in the way the Trust was being operated,

particularly in order to be in a good position to seek additional funding for the ongoing work of the Trust.

283. It was clear from the outset that the initial £10m was inadequate to provide long term support to the affected community, however it was not until the meeting with the Department of Health on the 7th September 1989, that there was any positive indication that more funds might be available in due course.

a. As above, the Government appointed four Trustees but did not seek to influence the selection of the Haemophilia Society nominees.

b. – e. The note of the meeting held on 7th September 1989 [MACF0000081_065] lists a number of areas where the Trust sought clarification of the Department of Health's view on various policies and approaches relating to the payments to beneficiaries. My only knowledge is based on a reading of this note.

Q115. Please describe the working relationship between the Macfarlane Trust and the Department of Health. Was there a particular point of contact? If so, who was that? Were you aware of any difficulties? If so, what were they, how did they impact on the running of the Macfarlane Trust and how, if at all, were they resolved?

284. I have no recollection of this.

Q116. Did you, or any others within the Macfarlane Trust, raise any concerns or issues with the Department of Health about the funding, structure, organisation or running of the Macfarlane Trust, or about the involvement of the Department of Health, or about any other matter? If so please explain what concerns and issues were raised and what the response was received from the Department of Health.

285. Other than the issues and matters raised in the meeting of 7th September 1989, I have no recollection.

Q117. Did you consider that the funding provided to the Macfarlane Trust by the Government was adequate? Please explain your answer.

286. As mentioned above, I believed that the £10m was totally inadequate to provide help and support for the infected community, however given the urgent need, I and the Society viewed it as a start in the right direction and at least an initial recognition of the cause of those infected through blood products.

287. For most of the first two years of the Trust, we did not know if further funds would be made available by the Government. Accordingly, as we knew that the community's needs were only going to increase over time, there was a need to balance generosity with a need to preserve the funds.

288. A key issue in the campaign that secured the £10m was a need to assist with mortgage costs and life insurance. It rapidly became clear that the funds available were totally inadequate for this purpose, as a relatively small number of payments

would both rapidly deplete the funds available and secondly would be inequitable within the community of beneficiaries.

289. Even with supplemental funding after my tenure at the Trust, I consider that all the Trust could really do was apply sticking plaster to many of the problems people were facing, however sticking plaster was better than nothing.

7.3 Identifying beneficiaries of the Macfarlane Trust

Q118.Whose responsibility was it to identify potential beneficiaries for the Macfarlane Trust?

Q119. How were potential beneficiaries of the Macfarlane Trust identified?

Q120. What, if any, steps were taken by the Macfarlane Trust to advertise its existence and/or raise awareness of its work?

Q121. Do you consider that more should have been done (and, if so, what and by whom) to reach people who might be eligible for assistance?

290. I do not have direct recollection, however from re-reading the minutes of meetings, identification of beneficiaries was jointly undertaken by the Haemophilia Society and Haemophilia Centres. Notices were placed in Society publications and posters in Haemophilia Centres asking people to come forward and register with the Trust. This was both before the MFT was formally established, and in the early period of its operation.

291. I believe that these were the most appropriate channels for reaching potential beneficiaries as most would have some contact with one of these organisations, communications through these channels were highly prominent as I recall, and I do not believe more could reasonably have been done at the time.

7.4 Eligibility for support and grants by the Macfarlane Trust

Q122. Who set the eligibility requirements (i.e. what an applicant had to show in order to be accepted as eligible) for the Macfarlane Trust?

292. I believe that this was set by the Trust deed as agreed with the Government, see also answer to Q 105 above, and was interpreted straightforwardly as needing to show that an individual had been infected through blood products or were associated with such an individual as set out in the Trust deed. The meeting of 7th September 1989 subsequently gave the Trustees a degree of additional flexibility.

Q123. Were they written down? If so:

a. Was the written policy publicly available or otherwise accessible to applicants? If not, why not?

b. Where or how could individuals access it?

c. Did the Government have a view as to the publication of policies about the eligibility criteria? If so, what was it?

293. I do not recall.

Q24. Were you, in your role, consulted about the eligibility requirements or otherwise involved in formulating them? If so, please provide details.

294. I was not specifically involved, some questions of interpretation were brought to the Trust Board and these were then referred to the Department of Health at the meeting of 7th September 1989 for guidance.

Q125: Was a medical opinion required to determine eligibility? If so, from whom and what issues was it expected to address? How were applicants alerted to the requirements for medical evidence?

295. I do not recall specifically, however I believe that evidence of a positive HIV test was required

Q126: Who set the procedural requirements an applicant needed to satisfy before being accepted as eligible as a beneficiary for the Macfarlane Trust?

296. I do not recall.

Q127. What were the procedural requirements for establishing eligibility? Did they change over time and, if so, how? In answering this question please address the following:

a. Was there a burden of proof on the applicant and, if so, what was the standard and how did it operate?

b. What kind of evidence or information did an applicant have to provide?

c. Was there a requirement for an applicant to have evidence of receipt of blood/blood products in their medical records (even in circumstances where the NHS had lost/destroyed the relevant medical records or they were otherwise unavailable through no fault of the applicant)? If so, why?

d. What other documentary evidence was required?

e. How were the requirements for evidence and any policies on the burden and standard of proof brought to the attention of applicants before they made their applications?

297. In response to (a) – (e) I do not recall.

Q128. Were these procedural requirements written down and publicly available? If so, where were they available and how could they be accessed by applicants? If not, why not?

298. I do not recall.

Q129. Who determined whether a person met the eligibility requirements to become a beneficiary for the Macfarlane Trust?

299. I do not recall.

Q130. Were you aware of any concerns about or dissatisfaction with either the substantive or the procedural eligibility requirements for the Macfarlane Trust? If so, what were these and what did you/the board do in response?

300. I do not recall any such during my tenure.

Q131. Please describe the process (if any) for seeking a review of, or appealing against, or complaining about, a determination that an applicant did not meet the eligibility criteria for the Macfarlane Trust. Relevant matters include:

a. Any right to give evidence or make representations in person;

b. Whether a representative was permitted to accompany the applicant;

c. The standard of review or appeal applied;

d. The criteria for members of review or appeal panels, including whether the original decision-maker was permitted to be present or make the decision;

e. The extent to which written reasons were provided; and

f. Any time limits or fees for the bringing of a review or appeal.

301. In response to (a) – (f), I do not recall any such during my tenure.

Q132. The Inquiry understands that the Haemophilia Society made grants on behalf of the Macfarlane Trust [MACF0000002_003 and MACF0000002_004]:

a. Is this correct? If so, how did it come about?

b. What was the basis upon which the grants were made by the Haemophilia Society? What criteria were the Haemophilia Society applying? Were these criteria written down and made available to applicants? If not why not?

c. What if any involvement did you have in determining applications for financial assistance and support at the Haemophilia Society on behalf of the Macfarlane Trust?

302. a. That is correct. This was in the period between the announcement of the award of £10m and the establishment of grant making process by the Trust. It was in order that there should be as little delay as possible in providing help and support in urgent cases. The alternative was that there would have been a six month period in which no payments were made.

In my opinion I believe that this was a generous act by the Society to use its own funds to bridge the gap until the Trust was fully up and running. These funds were reimbursed by the Trust once it was fully established.

b. I do not recall specifically, but I believe from reading the minutes that they were administered by the "Case Committee" of the Society. The Case Committee was a longstanding committee of the Society that looked at requests for financial assistance in cases of hardship from the whole haemophilia community. I do not recall who sat on the committee and I do not believe that the committee had formal policies, but I believe it had considerable discretion to make awards on a case by case basis.

c. None. I was not involved in any of these decisions.

Q133. The Macfarlane Trust annual report for the year ending 31 March 1989 suggests that there was frustration on the part of the beneficiaries as to the way the Macfarlane Trust discharged its functions [MACF0000045_030] . Why was this? How did this come to your attention?

303. I believe that the primary frustration at that time, was based on a misunderstanding of the nature of the Government payment and the role of the MFT. I believe that a number of beneficiaries thought that the £10m was to be divided equally amongst all the beneficiaries as a lump sum. I seem to recall that there had been a number of press articles at the time, which mistakenly suggested that this would be the case. I believe I recall this being reported to the Trustees.

304. I also believe that a number of beneficiaries felt that the payments that were made, could have been more generous.

Q134. Please explain who made decisions on applications for the Macfarlane Trust and how this changed over the time you were involved. In particular please explain:

a. When, if ever, staff employed by the Macfarlane Trust were able to determine applications, and which staff did so.

b. Which committees were formed for the determination of applications, how they were formed, who was chosen (and why) to sit on them, how often they met, who they reported to and the process they adopted for the determination of applications.

c. Which (if any) decisions on individual applications were made at board level and why?

305. a. The allocations policy published in October 1988 and attached to the minutes of the meeting of 24th October 1988 [MACF0000002_009] states that individual decisions on applications of less than £500 may be made on the authority of the Administrator and the Social Worker.

b. The Board established an "Allocations committee" at its meeting on 9th May 1988 consisting of: Rev Tanner; Mrs Leitch; Mr Palmer; Mrs GRO-A Mrs Norma Guy and Mr Knight. Mrs Leitch was a haemophilia social worker, Rev Tanner, Mrs Guy and Mr Knight were all members of the haemophilia community and Mr Palmer was a former senior official at the Department of Social Security and an expert on the benefits system. Mrs GRO-A sadly died shortly after being appointed to the Board.

I believe they met at least monthly, usually prior to a board meeting to which they reported.

c. From a re-reading of the minutes, as I recall, the only individual cases brought to the full board for decision, were a small number involving potential mortgage payments as these related to such a large amount of potential expenditure and also matters of principle.

Minute 89.26 of the meeting held on 14th March records that I and two other Trustees not on the Allocations committee, felt disadvantaged in approving cases involving questions of principle, without knowledge of the circumstances of the case. It was agreed that such cases would be brought to the board in future.

Q135. What were the procedural requirements an applicant had to satisfy when making an application for a grant? Who set these requirements? In particular:

a. What was the burden and standard of proof for such applications?

b. Were the procedural requirements reviewed? If so, by whom and how often? What were the outcomes of those reviews?

c. Were you aware of beneficiaries who were unable to satisfy the procedural requirements such as providing supporting documentation? What if any adjustments or provision were made for determining such applications?

d. Was medical evidence required? If so, why?

306. I was not a member of the Allocations Committee and so I did not have knowledge of the detail of the application processes.

a. I do not recall and have no knowledge of this.

b. I do not recall and have no knowledge of this.

c. I do not recall and have no knowledge of this.

d. I do not recall and have no knowledge of this.

Q136: What proportion of applications were granted (wholly or in part) and what proportion were refused?

307. I do not recall, as I was not a member of the Allocations Committee and so I did not have knowledge of the detail of the application processes.

Q137. Were reasons for refusing an application provided to an unsuccessful applicant?

308. I do not recall, as I was not a member of the Allocations Committee and so I did not have knowledge of the detail of the application processes.

Q138. Was there a procedure in place to consider applications made on an urgent basis? If so, what was that procedure? If not, why not?

309. I do not recall specifically, however as above, the staff had delegated powers to make grants within limits which could have been done on an urgent basis.

Q139. What practical support or assistance was given to applicants to help them in making applications?

310. I do not recall specifically, however I believe that in many cases the relevant Haemophilia Centre Social Worker, if one existed, would assist with the application.

Q140. Please set out the number of beneficiaries/applicants assisted by the Macfarlane Trust during your tenure.

311. The Annual Reports of the MFT show that:
In the Year to March 1989
£564,410 had been paid to 406 people in the form of regular payments
£498,201 had been paid in over 900 single grants to over 500 people;

312. In the Year to March 1990
£999,449 had been paid to over 600 people in the form of regular payments
£786,395 had been paid in 1,487 special grants to over 600 people.
In addition, a 'winter' payment of £400 was made to all those qualified amounting to 975 individuals and an additional cost of £390,000

313. Thus, in excess of £3m had been spent of the original £10m in the first two years of operation.

Q141. The Inquiry understands that the Macfarlane Trust made means tested regular payments to beneficiaries in the maximum sum of £20 per week [MACF0000045_030], rising to £25 in September 1989 [MACF0000045_029]. How was this figure set? Did the Macfarlane Trust seek any advice as to the cost of living with HIV? If so, from whom? [You may find MACF0000002_005 of assistance.]

314. On re-reading the minutes, this was first raised by Mr Knight at the inaugural meeting of the Board on 29 March 1989 "Mr Knight felt that we should keep in mind the usefulness of small regular payments, to supplement people's incomes – especially those whose regular income resources were limited." This had also been one element of our demands of the Government in the Society's campaign.

315. On re-reading the minutes, at the meeting of 7th June 1988 the Allocations Committee recommended an "extra needs payment to those whose income fell below certain defined levels, including those in low paid employment." This was initially set at £20 I do not recall how this figure was arrived at.

316. I do not recall if any specific advice was sought as to the costs of living with HIV.

Q142. Were the single grants means tested? If so, why?

317. They were means tested as described above.

318. I do not recall specifically, however I believe that the decision to means test was based on the legal advice shared at the initial meeting of the Trustees on 29 March 1988 [MACF0000002_2] that raised the question of equal distribution, and advised that this would not be possible under the Charities Act, and that individual circumstances needed to be taken into account for any grants and this included means testing.

319. It should be noted that the Trustees expressed regret at this limitation. [minute no 88.07]

Q143. What were the income brackets applied? Were the income brackets published? If so, where and how could the beneficiaries access this information? Were the income brackets kept under review? If so, how and in what intervals?

320. I do not recall.

Q144. In the board meeting on 7 June 1988 (which you did not attend), there was discussion about the trustee's drawing up criteria to be applied when considering applications for grants. [MACF0000002_005] Were such criteria drawn up during your tenure? If so, by whom? Were the criteria made available to applicants? If so how? You may also find [MACF0000002_009] useful.

321. I do not recall, but some criteria are included in the Grants Policy paper attached to the minutes of the meeting held on 24th October 1988 [MACF000000_009].

Q145. The Inquiry also understands that the Macfarlane Trust was actively considering whether it should meet the housing needs of its beneficiaries by granting 'equity sharing mortgages' [MACF0000045_030 and MACF0000045_029]:

a. Please outline the discussions that you were involved in on this issue, what your view was and why.

b. Were any such agreements reached with beneficiaries during your tenure?

c. Did the Macfarlane Trust seek legal advice with regard to the loans made by the Trust? If so, what did that advice say (please note that legal professional privilege has been waived by the Macfarlane Trust)? Did you agree with that advice? Did the Macfarlane Trust act in accordance with that advice?

322. In response to (a) – (c), I recall that the issue was discussed, but in spite of a reference made to myself, I have no recollection of my view at the time nor of any details of agreements made.

Q146. What if any non-financial support was available to eligible beneficiaries of the Macfarlane Trust? Was the availability of non-financial support made known to the potential beneficiaries, and if so how?

323. I do not recall that during my tenure at the Trust any non-financial support was available to beneficiaries. I am aware, as a beneficiary myself, that this changed over time to include such support as access to a benefits advisor.

Q147. In the annual report for the year ending 31 March 1990 [MACF0000045_029] it was stated that the staff were to be assisted by 'a small network of part-time Visiting Social Workers'. What was the role of these social workers? How were they recruited?

324. I do not recall any details of this.

Q148. During the board meeting on 7 June 1988 (which you did not attend), it was agreed that it would be 'inappropriate' to fund raise in order to support the work of the Macfarlane Trust. [MACF0000002_005] Did you agree with this? Please explain your answer.

325. Yes I did. I believed that it was solely the responsibility of the Government to fund the Trust, not least since I believe that it was the failure of government policy that caused the infected blood problems in the first place.

Q149. Did you agree with the Macfarlane Trust decision not to campaign for compensation for the beneficiary community? Please explain your answer. You may find [MACF0000002_019] useful.

326. Yes I did. I believe that the trustees felt campaigning was best left to the Society and that the MFT should focus on the challenge of distributing financial support to the affected community. As the minute states, there was already confusion in the media about the respective roles of the Trust and the Society. In addition, the Trust was hoping that in due course additional funding would be received from the Government and a political campaign might mitigate against this. In any case, I doubt that under the Trust Deed the Trust would have had the power to conduct an overtly political campaign such as that for compensation.

Q150. What steps did the Macfarlane Trust take to engage with and understand their beneficiary community?

327. The Trust started sending out newsletters to beneficiaries on its register from October 1988 as evidenced in the attachment to Minutes of meeting held on 24th October 1988 [MACF0000002_009]

328. From about that date onwards, there were regular outreach visits across the country to meetings of beneficiaries, normally organised by local haemophilia centres, but this also included meetings with specific groups such as the nascent Birchgrove Group in January 1989. Full details of visits are appended to minutes of the meetings of 22 June 1989 and 20th November 1989 [MACF0000002_016] [MACF0000002_019].

7.5 Relationship between the Macfarlane Trust and Haemophilia Society

Q151. During the meeting of the Haemophilia Society Policy Committee held on 9 November 1991 [HSOC0017239], concerns were raised regarding the relationship between the Macfarlane Trust and the Haemophilia Society. It was said that the Society was receiving telephone calls from people asking that it intercede with the Trust on

their behalf over grant requests. Could you please explain why there were concerns surrounding the relationship between the Haemophilia Society and Macfarlane Trust?

329. I do not recall.

Q152. In the minutes from The Haemophilia Society meeting of the Policy Committee held on 15 April 1992 [HSOC0017237], it was reported that a meeting had been held between the Macfarlane Trust and members of the Society, at which a better relationship and communication had been discussed.

a. Could you please describe the relationship between the Haemophilia Society and the different trusts and schemes? Did the Haemophilia Society keep in contact with any of the trusts and schemes on a regular basis?

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

c. Did the Haemophilia Society have input into whether particular procedures would be covered by funding from the Macfarlane Trust or the other schemes? If so, how?

a. I do not recall other than it generally being co-operative. I believe that David Watters, Graham Barker and Karin Pappenheim would have had regular meetings with the trusts and schemes.

b. I do recall that over time, a number of beneficiaries were unhappy at the way the Trust dealt with them, but I do not recall specific examples.

c. I do not recall.

Section 8: Other Issues

Q153. 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.

330. I have no recollection or knowledge of this.

Q154. 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.

331. I have no knowledge of this. My own personal hard copies of any Society or MFT papers would have been destroyed some years after ceasing to be a Trustee of these organisations. I retained a few copies of The Bulletin and some press cuttings for personal interest, I believe all relevant documents held by myself are either already held by the Inquiry or have been attached as exhibits.

Q155. Please explain, in as much detail as you are able to, any other matters that you believe may be of relevance to the Infected Blood Inquiry, having regard to its Terms of Reference and to the current List of Issues.

332. I believe that it has been the view of the Society, certainly from the time that I became involved, that the root cause of the infected blood scandal was clear, and this view informed the actions and positions of the Society throughout the period concerned.

333. This view was, that if successive governments, of all political persuasions, and relevant public bodies, had taken appropriate steps based on the state of knowledge at the time, and implemented promises and assurances made by ministers and officials, then there is a high probability that the great majority of those infected with HIV or HCV would not have been so infected. Accordingly, regardless of any legal liability, government has a clear moral responsibility to support and compensate those individuals and their dependents who died or have suffered as a consequence of their failure.

334. The Society, and the great majority of our members, did not believe that, for the most part, haemophilia clinicians were negligent. Time and time again, we were told that individuals did not want to take legal action against their doctors. By and large, haemophilia clinicians cared deeply about their patients and acted in good faith in their treatment. Accordingly, the focus of the Society's campaigns was always to persuade government to meet its moral responsibility for its negligent behaviour.

335. I would like to bring to the Inquiry's attention a range of matters that provide a deeper context to how the Haemophilia Society acted over the period I was involved with its work.

336. The Society was always a very small charity, with limited income and resources. It was not until the appointment of David Watters in about 1980, that the Society had any full time staff.

337. The level of funding was severely limited, and was mostly in the form of community fundraising, such as raffles, indeed I believe that for a time the Christmas Raffle was the largest single source of income, local events, individual fundraising efforts etc. This changed somewhat as the impact of the HIV epidemic amongst the haemophilia community grew and government grants, grants from charitable trusts and commercial donations became available.

338. At no time was the Society in a position to pay for its own scientific and medical expertise, and so at all times it had to take on trust, the advice given to it by clinicians and scientists within the haemophilia community. The Trustees were all lay individuals in this connection.

339. The Society had to make policy, and take decisions, based on the medical and scientific advice available to it as a group of lay individuals. As is frequently the case

with emerging threats, this advice was frequently confusing, conflicting, incomplete and with hindsight, some of it was incorrect.

340. I should also like to place the HIV and HCV campaigns in the context of the wider work of the Society. A significant proportion of the haemophilia community, and thus the Society's membership, were not directly impacted by infection with HIV or HCV and this proportion grew over time. For example, it was the case that the services that the Society offered particularly appealed to parents of young children with haemophilia. From 1985 onwards when viral inactivation of products became widespread, children should not have been infected, so by for example 1996, any family with a child with haemophilia under the age of 12, would not be impacted by the infected blood issue.

341. I make this point to illustrate that there were competing demands, from different elements of the membership, as to the direction of the time and effort of the Society. The Society had a wide range activities and services that the community as a whole benefited from, and used, including: adventure holidays for children; promoting information on living with haemophilia, including areas such as education, dentistry, physiotherapy, and exercise; assistance with benefit claims such as mobility allowance; supporting local groups for peer support; organising meetings, seminars and conferences for members; and fundraising. These "business as usual" activities had to continue whilst the campaigning work also progressed.

342. I would also like to make some points about the environment in which we were operating, particularly in the period 1985 -1996.

343. The sheer scale of pressure on the Society and the small number of staff was overwhelming. All communication was by post or telephone, and at times there would be hundreds of pieces of correspondence or phone calls each day, coming in from concerned members, or calls from the media.

344. The external environment was extremely fearful and hostile to anyone associated with HIV or AIDS. Having haemophilia became a marker for AIDS, we had members who lost their jobs, children stigmatised at school, families whose homes were vandalised. The staff of the Society, particularly David Watters, moved mountains to help in individual cases such as these. It also changed the way the Society had to work, for example we became careful to ensure that post from the Society to members did not have the word "haemophilia" on the post franking machine for example. All these pressures placed enormous strains on the staff over a prolonged period.

345. Individuals on the Trustee Board itself were also living under the personal pressures of living with haemophilia and HIV. No one could seriously suggest that the Executive Committee could not be taking the infected blood issue seriously, when so many of its own members were infected, and were working alongside friends and colleagues who they watched become ill and die, knowing that this same fate awaited them. During my time on the Executive Committee, at least six of my trustee colleagues died from HIV, and personally, another six of my friends from school also died.

346. I would contend, that for such a small charity, whilst the outcomes of our campaigns remain unfulfilled to this day, what was achieved was remarkable, and a testament to the staff and volunteers involved.

Supplemental Questions

Please consider the document "Haemophilia and AIDS: The Hidden Disaster. Aids Haemophilia and the Government" [HSOC0003459]:

a. Please describe how this document came to be drafted. What role, if any, did you have in this process?

347. This document was the basis of the claim to government in the Society's campaign for financial recompense in November 1987. As I recall it was drafted primarily by Dr Peter Jones and David Watters, with input from the Rev Tanner (Chairman), myself and possibly others. It would have been circulated to the wider Executive Committee for approval before publication.

348. It was a distillation of the Society's case, based on the evidence of need that we had identified at the time, and as a result of the Government's intransigence in acceding to any financial support for those infected as a result of successive government's failures.

349. Based on the advice that we had received from a number of sympathetic MPs, a clear statement of need, together with a costed proposal for financial support, was put together. It was this document that was the centre of the all-party meeting at Parliament on 5th November 1987 and was presented by Dr Jones, Rev Tanner, Mr Julian Miller and myself, to Members of Parliament.

350. Less than two weeks after this meeting in Parliament, the Government performed a U-turn and announced the £10m that led to the establishment of the MacFarlane Trust.

b. At page 2 of the document it is stated:

"We are asking the Government to help restore the quality of life of people with haemophilia and HIV infection.

At Government's suggestion the Society has already explored the question of redress through the legal system and has been advised that claims for compensation as such are most unlikely to succeed because of the difficulty of proving negligence. In any case, the Society is advised that any solution which may be provided by the courts will not be available in the short term. However, the needs of families are immediate. The Society is therefore looking to Government as the only available source of support, recognition and recompense." Is it correct that the Government suggested to the Society to explore the question of legal redress? If so, please identify who proposed this, when and what precisely was said.

351. Ministers and officials consistently had said that there was no provision for "no-fault compensation" by the Government and that compensation should be sought through

the courts. I have referenced elsewhere the Written Answers from January 1987 [WITN45000012] and others that make this point. This position had been made clear, I believe, in numerous conversations between the Society and officials and ministers, and in Parliamentary exchanges on the issue. Indeed, the Minster for Health Mr Tony Newton, when he made the statement to the House of Commons on 16th November 1987 announcing the payment of £10m that led to the establishment of the MacFarlane Trust, reiterated this and said:

> "As the House knows, the position under successive Governments has been that, while compensation may be sought through the courts if there is a question of negligence, there is no state scheme of "no fault" compensation for those damaged by medical treatment." [Exhibit WITN45000029]

352. It is my recollection that the Prime Minster Mrs Thatcher had said something similar previously, as is reported in Chapter 10 of "the End of Innocence" [WITN4500009] by Simon Garfield:

> "Margaret Thatcher had always insisted that the correct course of redress was through the courts and it was clear she had sought advice on the matter."

c. Why did the Society tell the Government that they had been advised that litigation was unlikely to be successful?

353. The Government's stance, that legal action was the appropriate route to take, allowed them to wash their hands of any responsibility or accountability for providing financial support, let alone restitution, to all those whose lives had been devastated by a failure of government policy. It was for them a 'get out of jail free card'.

354. The Society had to point out to the Government that they were being disingenuous in taking this position as both they, the government, and the Society, knew that this was an unrealistic option in providing any kind of help in a timely manner to the community. It was a cynical position taken by the government, who knew perfectly well that any legal action would be uncertain in outcome and lengthy in its proceeding.

355. Legal action was just not an option given the immediate needs for the many hundreds of the community who were becoming ill and dying, thus the Society pursued as an alternative, a political campaign based on the moral imperative that the Government should help, as infection had been a result of Government policy failure.

d. Please provide any information that you have about this document that you consider relevant to the Inquiry's Term of Reference.

356. Reviewing the document, I believe it to be as compelling today as it was when we wrote it nearly 35 years ago, in how it sets out the challenges and needs faced by the community at the time. I also believe that the calls we made in the document, for mortgage protection, financial support for the bereaved and dependents, and compensation for "the unquantifiable loss suffered", have still not been adequately, nor appropriately met, and that the case still stands.

2. Please consider the document "Haemophilia and AIDS: a briefing paper" [LDOW0000295]:

a. In your view, is this document accurate in its description of why the Society was pursuing the Government for funds? If it is inaccurate, please explain what the correct position is.

357. Yes, from my review, this is an accurate description of the Society's claim for compensation as at October 1989. It was written prior to the meeting between senior Conservative MPs and the Prime Minister Mrs Thatcher in November 1989, referred to in the account of the campaign contained in Ch 10 of the 'The End of Innocence" [WITN4500009]. This led to the first 'lump sum' payments made by the government in 1989.

b. How did the Society come to state that almost 500 people did not qualify for legal aid?

358. I do not recall, but I believe that we would have been advised of this by the Solicitors acting for the claimants. It is probable that legal representatives of the claimants such as Mark Mildred, may be able to assist the Inquiry in much more detail regarding the legal and litigation aspects of the campaign.

c. When did the Government indicate to the Society that they were "not yet convinced of the need to settle the matter out of court" ? Who informed the Society of this matter? What did the Government say when conveying this point? Did they rely on the Society's advice that the Society had already shared with the Government? What was the Society's response?

359. These matters were likely to have been the subject of conversations between Department of Health officials and David Watters and the Chairman Rev Tanner. I was not party to any of these discussions and so cannot assist in answering these questions. Having said that, the response was to pursue the political campaign, of which this paper was a key element and the meeting with the Prime Minister as referenced above.

Statement of Truth

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

Signed GRO-C

Dated 22 April 2021.