Witness Name: David George Watters
Statement No.: WITN3429001
Exhibits: WITN3429001–WITN3429030
Dated: January 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DAVID GEORGE WATTERS

I provide this written statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 August 2020.

I, David George Watters, will say as follows:-

1. My name is David George Watters. My date of birth is GRO-C 1945 and I reside at GRO-C I provide this statement in my capacity as former Coordinator (later General Secretary) of The Haemophilia Society, London. I was employed by The Haemophilia Society ("The Society") between 1981 and 1994.

2. I have addressed the requests raised by the Inquiry in the sequential order in which they are put to me in the Inquiry's letter dated 4 August 2020.

Section 1: Introduction

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

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

3. I was born on the Island of Hoy, Orkney, on GRO-C 1945. I attended Brims Primary School and Stromness Academy to Scottish Higher Certificate level. Between 1964 and 1968 I was a lay worker for the Church of Scotland in Crieff, Glasgow, North West Highlands and Edinburgh. Between 1968 and 1972 I was employed as a Social Worker in St Martin in the Fields Social Case Unit. In 1972 I became the Director of The Threshold Centre for Single Homeless in London and ceased that role in 1976. Between 1976 and 1981 I was a Director at Alone in London Service. In 1981 I was appointed as the Co-ordinator of The Haemophilia Society. That role later became the General Secretary and my employment at The Haemophilia Society ceased in 1994, as a result of my role being made redundant. Between 1995 and 2005 I was the CEO at the Primary Immunodeficiency Association in London. Upon leaving the Primary Immunodeficiency Association in 2005 I retired. Between 2005 and 2012 I was a part-time Executive Director at International Patient Organisation for primary Immunodeficiencies based in Cornwall on a consultancy basis.

4. In addition to the above, at various stages I held non-salaried roles, for example, between 1980 and 1995 I Chaired the Supplementary Benefit (Social Security) Tribunals. In 1980 I was also appointed a Justice of the Peace in inner London and this role ceased in 2000. I have held the role of Church Warden at various times in London and Cornwall. I also served on the EMEA Committees between 1996 and 2005.

5. I also think it is appropriate for me to set some wider context as to my appointment to The Haemophilia Society in 1981. Before being appointed, I went through a very rigorous selection process. I attended multiple interviews with the Board and

the Board was not unanimous in its decision to appoint an external senior member of staff and, indeed, on the day I arrived the two part-time secretaries had not been advised of my appointment and I had no desk, and no office. At the time of my joining the organisation itself, I felt it was some 30 years behind the times in so many ways, and this added tension did not help the necessary growth and development of the organisation which quickly became apparent.

6. At all times during my tenure at The Society, whilst I was responsible for managing matters, the Board were very much responsible for all decisions made and the direction of travel adopted by The Society. I was answerable to the Board and I did as directed by the Board.

7. As I am sure the Inquiry has already noted, the early 1980s was a very different age. There were not as many questions asked as there are today and one tended to have a higher level of trust in government and others in authority. There were no computers in small organisations and communication was so very different, and so much more difficult than it is today.

Section 2: Previous Experience

Please consider the evidence which you gave to the Penrose Inquiry. Please confirm whether the contents of your evidence to the Penrose Inquiry are true and accurate. If there are any matters contained within the letter from Thompsons sent on your behalf prior to your oral evidence [PRSE0003528] and your oral evidence to the Penrose Inquiry [PRSE0006087] that you do not consider to be true and accurate, please explain what they are.

Please confirm whether you have provided any evidence or have been involved in any other Inquiries, investigations, criminal or civil litigation in relation to the human immunodeficiency virus ("HIV") and/or Hepatitis B virus ("HBV") and/or Hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-jakob disease

("VCJD") blood and/or blood products. If you have, please provide details of your involvement and copies of any statements that you made.

8. As far as I can recall the statements and evidence provided are correct. If there are any areas relating to the questions asked of me by this Inquiry that I am now uncertain of, given the passage of time, I have identified that below. I have not provided any evidence to anybody else in the meantime on anything relevant to the Infected Blood Inquiry's terms of reference. I have, however, appeared on various television programmes in respect of the contaminated blood scandal.

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

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

9. As far as I can recall, the Society was always there to provide for and promote the best interests of people with Haemophilia, and that didn't change during my employment. Even though we had to devote a lot of resources to HIV, AIDS and Hepatitis, the core activity was always representing the best interests of people with Haemophilia.

10. The Inquiry has provided me with a copy of a Haemophilia Society publication, Group Seminar Proceedings from December 1981 [WITN3429002/PRSE0003316]. On page 12 of that document there is reference to the aims and objectives of The Haemophilia Society based on a talk provided by a member of The Society's Executive Committee, Ken Milne, on 15 March 1981. The Society's objectives were listed as:

    a) To provide a fellowship for sufferers from Haemophilia and allied conditions, their families and those concerned with their health and welfare;

    b) To safeguard social and economic interests of such sufferers;

c) To promote the study of the cause and treatment of haemophilia and allied conditions;

d) To gather and publish information useful to sufferers and the general public.

e) To co-operate with the medical and allied professions for the furtherance of the objects of the Society;

f) To co-operate with any other Societies or bodies having similar aims;

g) To provide financial help where necessary and practicable;

h) To do all other things which may legally be done in the furtherance of the Society's objects.

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

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

11. When I joined there was a Board of Trustees and the Executive Committee. The Board of Trustees and Executive Committee were exactly the same body, there was no difference between them. The Executive Committee was the supreme decision making body of The Society. The Council sat below the Executive Committee. The Council consisted of two representatives from each local group. There is a simple illustration of the structure of The Society as at 1981 in WITN3429002/PRSE0003316. In the same document, there are 28 local groups listed on page 16. By 1988 there were 30 local groups referred to in the Annual Report [WITN3429003/HCDO0000276_021]. Information flowed to and from the membership and information flowed to and from local groups of The Society.

12. The Council would meet with the Executive Board two or three times a year. Whilst the local groups were often in correspondence with each other they rarely met outside the meetings with the Executive, as far as I am aware. There were

also regional meetings where the Executive Committee would not just meet with representatives from the local groups but would also meet with the membership of the local groups and anyone else who was interested in the work of The Society, for example, mums, dads, partners. Whilst the structure had its limitations, for example a lack of basic equipment, it worked well on the whole with the one member of full time and two part time members of staff.

13. Individuals became members of The Society by returning a simple form and they did not even have to pay at that stage. At one stage the membership fee was 50 pence or £1, I cannot recall exactly. I know it cost more to administer the fees obtained through the membership than what was actually received. It is also important to remember that only a small minority of individuals in the UK living with Haemophilia were members of The Society. In February 1983, it was reported in the Group Seminar Proceedings that there were 5,000 individuals with haemophilia in the UK and only 1,500 of those were members of The Society [WITN3429004/PRSE0003074].

14. My relationship with the majority of the Board and the staff was good. There were two members of the Board who saw my role as totally unnecessary, and after some time they walked out of a meeting and were not seen again. They had effectively lost because the other trustees were supportive of the role and my appointment. It wasn't me that they were opposed to, it was the appointment that they were opposed to which I think they saw as an erosion of their power. The relationship with the Council was always excellent. It was a very familial situation.

In your oral evidence to the Penrose Inquiry, you confirmed that you held two roles with the Society; the first being Coordinator from 1981 to 1986, and then General Secretary from 1986 to 1994 [PRSE0006087, page 5, paragraphs 11-16]. Please explain what your responsibilities were in relation to each role, who you reported to, and how the roles changed over time (if at all).

15. I joined as Co-ordinator, that job title was negotiated as a term that did not have the word Secretary in it so did not upset the Honorary Secretary, but eventually I became the General Secretary. I cannot recall whether I remained General Secretary to the end or whether I became Executive Director or Chief Executive or something like that. It did not really matter what the job was called, it was more what I was doing that was of importance.

16. Whilst my job title changed from Co-ordinator to General Secretary nothing about the role changed. It was the Board that felt that I was doing a good deal more than co-ordinating, and felt that the change in title would give the organisation better standing. On page 12 of the 1986 Annual Report [WITN3429005/HCDO0000276_033] the change of title is described as "*The Co-ordinator experienced a re-incarnation and emerged as the General Secretary, a title which describes more accurately his present position in the Society and the functions he performs.*

He is responsible for the day-to-day administration of the Society's office and its staff, as well as for general communications with the Society's members by correspondence and telephone. In addition, he has special responsibilities in connection with Mobility and Attendance Allowances, often supporting members personally when they attend Appeal Tribunals".

17. When I joined The Society I had no idea of what the role was going to entail. I have to admit, I thought the organisation would have been a bit sharper than it was. Most of the trustees were amazing people. A number of these individuals are no longer with us. People like, Howard Abrahams who was an outstanding Accountant, John Prothero who was a fairly senior Civil Servant, Peggy Britten whose son was a consultant in blood transfusion in the United States, Ken Milne who was also high up in the Civil Service. There were so many people there whose lives had been totally transformed by the arrival of Factor VIII. I attach as

exhibit [WITN3429006] a table detailing each of the individuals at The Society during my tenure and provide some information in respect of each as I recall it.

18. I initially thought that I would be joining a fairly well oiled organisation. It was my understanding that the organisation may possibly have been creaking a bit from what I had picked up in my interviews, but the expectation was that I would take it and run with it. However, when I joined, in fact I discovered I had a very ancient automobile that I had to take apart and put together again. I always worked at least 8.00a.m. to 6.00p.m. A large part of my role was building up the organisation and helping members to trust the organisation and see the organisation had a function and a purpose. I wanted to show that The Society was interested in learning about haemophilia and helping people with haemophilia, knowing about problems and helping out with cash grants, for example, where we could.

19. In a nutshell, at the time I joined The Society, I do not believe it was fit for purpose. I say that because of its lack of outreach and its lack of grasp of the big issues. It was quite introverted really, and difficult when the Board of Trustees, all of whom either had or were one step removed from haemophilia (i.e. did not have haemophilia but had close links to somebody with haemophilia). My role changed as the organisation expanded and grew and it was changed beyond belief with the arrival of HIV. Of course, I was totally unaware of HIV, as was everybody else, when I joined the organisation.

20. When I joined The Society I was liaising with the membership, with members of Council in particular, learning the ropes from the Board of Trustees, spending time out in the field with Centre Directors, learning to know the ins and outs of Haemophilia and how it affected people and how different treatments were needed and how joints were affected.

21. I also had the whole tax reclaims to sort out and that took a considerable amount of time, because they had not been done for about 10 years. There were also other groups that I needed to liaise with and develop a relationship with, like the Social Workers Group and the Nurses Group. I needed to better understand what their needs were and what their views were.

22. At a very early stage I discovered that The Society had never done anything at all about welfare benefits for people with haemophilia and the membership cried out for help with mobility allowance and in some cases attendance allowance. I was also a serving Justice of the Peace and so I had a fair grasp of how things worked and I could read a document and understand it. I often attended tribunals on behalf of the membership. I became something of an expert with a reputation for winning my cases in tribunals. I often spent complete days representing people with haemophilia at disability appeal tribunals in support of their claims for mobility allowance with considerable success. The claims for mobility allowance came largely from those whose joints had been badly damaged by haemophilia, but this was by no means exclusively the case. Latterly it became very difficult to obtain mobility allowance for children who had benefitted from prophylaxis. In my time, I also achieved a Commissioner's Decision in favour of awarding mobility allowance to people with haemophilia which made the task a little easier.

23. In those early days although the numbers of staff started to increase we still did not have many hands and there was an enormous lobbying campaign with the press, with politicians and everyone else, taking up huge amounts of time. We were relying on a typewriter to bash out a letter, and writing to 300 MPs would take a very long time! Happily we eventually got into the 20th century and got computers which made it all easier, but I sometimes wonder how on earth I got through those early days really because the emotional demands were incredible.

24. As the situation with HIV and AIDS started to develop I was arriving in the office at seven o'clock in the morning and would have an hour to catch up on

yesterday's admin before the phone started ringing off the wall at eight o'clock. I would have schools and school teachers ringing to say, "*we'd got a kid who's got haemophilia and he might have AIDS, the parents are refusing to send their children to school*", I would then need to clear time in my diary and go out and attend some of these schools in the evenings to meet parents and teachers, for example. The membership were naturally out of their minds with worry about the whole situation and I could easily have spent all of my days on the telephone as a kind of telephone counsellor, but I had a great deal more than that to do and, at this stage, on reflection, quite how I got through it all I am not sure.

25. Throughout this time, I had a secretary to assist me but nobody else to whom I could delegate any of the activities. That situation changed slightly when The Society moved properties to the Westminster Bridge Road address in October 1986. At that stage things developed and we had a good accounts department with two staff and a HIV and AIDS worker, Jonathan Cooper. We also had somebody who worked in reception so at least I did not have to answer the doorbell as well when the postman came, for example. I cannot emphasise enough that during this period of The Society's history it was most certainly not a vast organisation and I was most certainly not sitting in a very well equipped luxury office, things were very, very different then. Throughout my period at The Society I reported to the Chairman, Reverend Alan Tanner. I would meet with him on a weekly basis.

When did you begin producing written "General Secretary's Reports"? How often would these be produced? You might be assisted by documents 41 to 50 above which are the reports the Society has disclosed to the Inquiry.

26. I cannot recall when I began producing the General Secretary's Reports or how often these would be produced, unfortunately. I would produce them for the monthly Board meetings generally.

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

27. The General Secretary's Reports were the main information document in order to disseminate anything to the Executive. However, we also regularly spoke on the telephone. Each meeting would have an agenda and we would talk through the agenda at each meeting, it should be remembered that these were not individual's full-time roles. These meetings often took place after others had completed a full day's work. If there was something urgent that arose between meetings, I would generally telephone the Chairman and take directions from him and then take it from there. There was no email at that stage, therefore, telephone was the quickest way of communicating. At the time detailed telephone notes would not be taken as these were regular telephone calls and record keeping was not what it is today. The Society was such a small organisation, as I was the one who would action the information/instructions received over the phone, I would retain the information in my head. At the time, there was no need to note the call and nobody to hand over to.

28. In relation to the structure generally, if something urgent arose, I would generally raise it with the Chairman, however, if it was an accounts questions, for example, I would go directly to the Treasurer. If it related to blood products, I would likely go to the Chair of the Blood Products Sub-Committee, and so on. I would always keep the Chairman in the loop so that he was never disadvantaged or taken by surprise.

3.1 Committees and Advisory Bodies

Please list all the different committees and advisory bodies that you recall were set up within the Society and describe the purpose, functions and responsibilities of each committee or advisory body. Please include a description of the Treatment and Care Committee and the General Services Committee.

29. At all stages there was a Medical Advisory Panel, and I believe the Blood Products Committee, and the Case Committee. I am aware that I informed the Penrose Inquiry that I did not think that the Blood Products Sub-Committee existed when I joined The Society, however, I now believe that it did. There were also other sub-committees as the needs arose. For example, if fund raising was in difficulty we would set up a fund raising sub-committee, there is also reference to a Case Committee and a Research Grants Committee in February 1984 [WITN3429007/HSOC0029476_033] and Policy Committee in Executive Committee minutes dated 14 November 1991 [WITN3429008/HSOC0010385]. In essence the committees were often established so that there was somebody else to share ideas with me because at the end of the day I was responsible for fund raising, staff welfare, recruitment of staff, management of the office, equipment, the building, as well as everything else. I would more often than not attend those sub-committee meetings, however, it was mainly to minute the meetings.

30. The Blood Products Committee. The purpose of this committee was to keep under review and, in particular, to be constantly on the back of the Department of Health about the achievement of self-sufficiency in the United Kingdom. Had we been self-sufficient in the late 70s, I have no doubt, that the outcome would have been very, very different. I do not mean that we would not have been in a situation where we had no Hepatitis and no HIV, but it would be much, much less and that's where successive governments, and successive Ministers of Health really failed us down the line.

31. The Case Committee. The purpose of this committee was to consider the giving of grants to families in need. I have no recall of members, however, I do recall that the Committee would consider applications and then place anonymous proposals before the Executive Committee for consideration.

32. The Medical Advisory Panel. This was a panel of leading clinicians in the field whom The Society could turn to whenever necessary to request their opinion and advice in relation to developments in the treatment of haemophilia.

33. I have been asked to comment on the Treatment and Care Committee and the General Services Committee. Unfortunately, I cannot recall the detail of either of these committees, however, I would assume that the Treatment and Care Committee dealt with the standards of treatment and care across the country, because certainly in the early days they were not consistent. I have no recollection at all of the General Services Committee.

3.1.1 The Medical Advisory Panel

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.

34. The Medical Advisory Panel existed in some form when I first joined the Society. There was no structure to the panel at that stage. Some would say it was not a panel as such. When I joined The Society the Medical Advisory Panel was pretty informal. The panel undoubtedly needed to be more formal and it took more than a little time to arrive there. Unfortunately, due to the passage of time I cannot recall the exact timetable of events.

35. In an article titled "*The functions of The Haemophilia Society",* in a 1982 Bulletin [WITN3429009/PRSE0000709, page 6] the Medical Advisory Panel is described as having "*…no executive role in the Society but we would ignore their advice at our peril! There is a fairly continual exchange of information and advice between the Officers and the Panel, although the formal meetings with them as a Panel are few. Their support has enabled us to open many doors that would otherwise have been closed to us".*

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.

In a brief on the Medical Advisory Panel, dated 7 November 1991 [HSOC0010470], you state that the Medical Advisory Panel consisted "*of "favoured" Reference Directors plus, more recently, other Centre Directors.*" What did you mean by "*favoured*" Reference Directors? Who were the *"favoured"* directors to whom you were referring?

36. When I first joined The Society I would make contact with various Reference Centre clinicians at the instruction of the Executive Committee and seek their advice. These individuals, were effectively the existing membership of the Panel. Individuals knew that they were members of the Medical Advisory Panel albeit there was no structure as such to the Panel, for example, there were no terms of reference at that early stage. I believe that the membership of the Medical Advisory Panel had evolved over time. I, therefore, felt that it was necessary to include a wider category of clinician into the Medical Advisory Panel. This was discussed with the Executive and it was decided that the structure of the Medical Advisory Panel should be formalised. It was also important to ensure that there was representation from a variety of angles, not only from the larger reference centres, but also from some of the smaller centres. We were looking for some of the panel to be more scientific and some of them to be more clinical so that we had a better understanding. All members of the panel would also have been members of the UKHCDO.

37. I have been asked to comment on the term "*favoured*" in the document that I created on 7 November 1991. Unfortunately, I do not recall creating this document, however, it is likely that I was simply referring to known clinicians at the time. Clinicians that The Society would regularly seek advice from. It is likely

that I would have been referring to the likes of Arthur Bloom, Peter Jones, Elizabeth Mayne, and Charles Rizza.

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

38. Unfortunately, I have no recall of my comment in this document. I could speculate, that I was simply referring to the fact that the Medical Advisory Panel, up until that point, had been quite informal and needed to be formalised.

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?

39. I would say it is erroneous to say that the Medical Advisory Panel did not meet until 1988, I am pretty confident that they met before this, however, I cannot be certain. I understand that this information has come from a letter to the Penrose Inquiry and I have also been referred to a document I created in 1991 in respect of the Medical Advisory Panel [WITN3429010/PRSE0002325]. In that document I wrote "*The Panel did not meet until 1988 when it was felt that advantage could accrue from meeting but over the past three years the usefulness of those meetings has been questioned*". However, from memory, I believe that the Medical Advisory Panel would have met before 1988.

40. The Chair and the Executive Committee would be the ones who would decide when and about what matters the advice of the Medical Advisory Panel would be sought. A number of factors would be taken into consideration in deciding which steps to take or whom to contact. For example, the Mail on Sunday article in May 1983. In that instance I immediately contacted the Chairman and it was agreed that we contact Professor Bloom for his advice; I cannot now recall whether it was the Chairman or myself who made the initial contact with Professor Bloom. Due to the urgency of the situation at that time the advice of the panel as a whole was not sought.

41. In my evidence to Penrose, I stated that "*I think I had been to church and I came home and there was the Mail on Sunday. The first thing I did was talk to the chairman of the Haemophilia Society and then I think we had a conference call with Professor Bloom to decide on the best course of action.*" I cannot recall exactly whether it was me or the Chairman who had the initial contact with Professor Bloom, however, document WITN3429011/BPLL0001351_089 is a

letter from Rev Tanner to Professor Bloom dated 26 July 1983 and states "*I intend to apologise for not having been in contact with you directly when we were seeking your advice about the statement we made regarding AIDS. We were very grateful indeed for your preparing a statement for us so quickly because that gave us a definite Society policy regarding AIDS and helped to allay a good deal of anxiety among our members".* This implies that the Chairman did not have any contact with Professor Bloom, however, I cannot recall this categorically. Rev Tanner also goes on to ask if Professor Bloom "*would wish to add anything to the statement which you prepared for us, or whether you think this is still sufficient without amendment*". I cannot recall whether Professor Bloom responded to this correspondence. This was not the only opportunity that Professor Bloom was given to amend his earlier advice, if he felt it necessary. I had also written to him on 19 July 1983 [WITN3429012/BPLL0001351_084] and stated *"You will recall that early in May you were kind enough to provide us with the gist of our statement which was issued to all members of the Haemophilia Society. While we do not believe that the situation has changed to any extent in the UK since that time, we did however wish to give you an opportunity to issue any amending statement which you may care to let us have particularly in view of the World Federation of Haemophilia Medical Board report on AIDS which was presented by Doctor Shelby Dietrich in Stockholm*". Again, I cannot recall receiving a response to this letter.

42. Again, it must be remembered that technology in the 1980s was not as it is now. All contact was usually initially by telephone, or by fax machine. In the event that the advice of the wider panel was required, it would be a matter of sending a letter to each of them if it was non-urgent, or it would be a fax if it was urgent. An example of this can be seen in document [WITN3429013/BPLL0001351_076] where I wrote to the Medical Advisory Panel on 9 May 1983 as a follow up to the advice received from Professor Bloom and in advance of a meeting with Geoffrey Finsberg, of the Department of Health and Social Security on 20 May 1983. The letter stated:

It is our intention to raise the following matters at our meeting with him:-

(a) A definite commitment to UK self-sufficiency in blood products.

(b) An assurance that there will be no immediate ban on the importation of US blood products.

(c) The possibility of the work at Elstree being further assisted in such a way as to make self-sufficiency possible earlier than 1985/86.

(d) Government support for research into AIDS in the United Kingdom.

The Chairman has asked that obtain any view you may hold on those matters and also any other subjects which you feel we should raise at this time which relate specifically to AIDS."

43. If we needed to get them all together in one room at one time to discuss a particular matter, it would be a telephone call in order to sort a convenient date. In the event that the Medical Advisory Panel was convened they would discuss the issues in hand and provide The Society with advice. From my recollection there would always be a consensus on the decisions to be made and the advice to be provided.

44. I have been asked if some members of the Medical Advisory Panel had more influence that other members and if so who carried more influence. Professor Arthur Bloom was the Chair of the UKHCDO and he carried a lot of sway, in that he was also the Chair of the Panel. The Medical Advisory Panel was chaired by the Chairman of The Society from time to time also. In the unlikely event that there was a dispute between the members of the Medical Advisory Panel, or they were unable to reach a consensus, then the Executive Committee would be responsible for determining the correct course of action for The Society. However, as I have stated above, I cannot recall an instance where the Medical Advisory Panel failed to reach a consensus.

45. Any advice received from the Medical Advisory Panel would be passed to the Chairman either by fax, telephone or letter. That advice would then be disseminated to the Executive Committee as would be evidenced in The Society minutes. I have been asked 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? This is a very wide question, and given the passage of time, I have no distinct recollection that would be helpful to the Inquiry. However, this information should be contained within The Society minutes.

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

46. Generally speaking, the Panel would convene two or three times a year, and there would be a Board member and usually the General Secretary, myself, in attendance. I was usually appointed the minute taker. As a rule, it would only be the Medical Advisory Panel or the Chairman or members of the Executive Committee in attendance. However, I believe, that there was one meeting where we invited a representative from a pharmaceutical company to attend and explain something in relation to a new form of treatment. Unfortunately, I have no further recollection of that particular meeting and cannot recall roughly when this was.

Why did the Haemophilia Society decide that the Medical Advisory Panel should meet in person? Please describe how the role of the Medical Advisory Panel changed over time from 1988.

47. As stated above, I believe that the Medical Advisory Panel met before 1988. It was decided that the Medical Advisory Panel should begin meeting in person as a result of the formation of the terms of reference, that can be found in document WITN3429014/HSOC0010470. It was felt essential that the Medical Advisory

Panel became more focussed in its support of The Society and in order to do that the formalised terms of reference were drafted. I cannot recall any other specific changes to the role of the Medical Advisory Panel, and up until receiving the documentation in order to respond to the Inquiry's Rule 9 I had forgotten about the introduction of the terms of reference.

In your role as Coordinator, and later General Secretary, of the Haemophilia Society, what were your role and responsibilities in relation the Medical Advisory Panel and in directing, communicating and receiving advice from the Medical Advisory Panel? Were you able to seek advice directly from the Medical Advisory Panel?

48. In essence I was a channel of communication to and from the Medical Advisory Panel and facilitated meetings. I would never have gone directly to the Medical Advisory Panel to obtain advice. I would have always gone through the Chairman in the first instance. It may have been me who then later contacted the Medical Advisory Panel and explained that The Society wished for them to provide specific advice.

In your evidence to Penrose [PRSE0006087], you describe the Haemophilia Society's reliance upon the Medical Advisory Panel's advice. 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?**

49. Advice would only generally be sought in the formal meetings with the Medical Advisory Panel. However, in urgency, on occasion the advice of an individual member of the Panel would be sought. The decision to seek advice would be down to the Chairman and the Board of Trustees, the Executive Committee.

50. If contacting an individual member of the panel a number of factors would be taken into consideration. For example, the experience of that individual clinician, and the advice that was being sought. In the event that an urgent query needed to be dealt with, I anticipate that the various Panel members would also telephone each other in order to discuss that advice before finalising it and providing it to The Society. It would not be a matter of me phoning each member of the Panel individually, I would generally telephone one member and if they felt that further advice from their counterparts was required, they would then make those telephone calls themselves. As in many situations, those with more experience, would generally have slightly more influence than the more junior members of the Panel. The more experienced members of the Panel had generally been dealing with these matters for a longer period of time. The advice of the Medical Advisory

Panel would then be relayed to the Chairman, either by telephone, or in a letter. The advice obtained from the Medical Advisory Panel, provided to the Chairman, would then be disseminated at the next Board meeting for the Executive Committee. Anything discussed at a Board meeting would then be minuted within the relevant meeting minutes.

In your evidence to the Penrose Inquiry, you stated that when members of the Medical Advisory Panel disagreed with each other, the Haemophilia Society sought to take "*the middle course*" [PRSE0006087, page 29, paragraphs 18-20]. Please confirm:

a. What you meant by taking the "*the middle course*"?

b. Who decided which advice should be followed?

c. How the Haemophilia Society determined "*the middle course*", including whether this was:

i. by majority, and if so, whether this refers to the majority opinion of the Medical Advisory Panel or the decision makers in the Haemophilia Society [PRSE0006087, page 29, paragraphs 14-16]; or

ii. by following the views of the Chair of the Medical Advisory Panel [PRSE0008087, page 30 paragraph 11-12]?

51. As stated above I cannot now recall instances where the Medical Advisory Panel failed to reach a consensus. In my evidence to the Penrose Inquiry when I refer to "*the middle course*", I meant the consensus or the majority. In the event that this situation arose it would be the Board, the Executive Committee, that would make the ultimate decision and decide which advice should be followed. At all times, in relation to clinical matters, The Society was guided by advice received from clinicians on the Medical Advisory Panel. None of the trustees, members of the Board or the Executive Committee and none of The Society's staff had any clinical qualifications.

As far as 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.**

52. As stated above, I cannot recall any instances where The Society relied on its own judgement when deciding whether or not to formulate a policy on the basis of the Medical Advisory Panel's advice; or when The Society did not follow the Medical Advisory Panel's advice; or when members of the Medical Advisory Panel disagreed with the advice of the Chair of the Panel; or when The Society did not follow the advice of the Chair of the Medical Advisory Panel. As far as I recall, the situations simply did not happen. As stated at paragraph 35 above, the opinion of the Executive Committee in 1982 was that The Society would ignore the advice of the Medical Advisory Panel *"at [its] peril"*.

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 meeting 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.

53. This document was signed off by Graham Barker, I have no recollection of being part of this and I did not author the paper. This matter was a distinct policy matter and Graham Barker was the Policy Manager for The Society. I do not have any categorical recall of the situation, however, I do recall a statement at some stage about difficulty the Centre Directors may have had in giving independent advice rather than the advice of the UKHCDO.

54. I do not believe that this would have constituted a conflict of interest, because the individuals were there as a result of being Senior Reference Centre Directors, or highly experienced Centre Directors who served on two bodies. In my opinion it would either be an entire conflict of interest, or no conflict of interest at all, because everybody was attempting to serve the same interest. I am reluctant to start speculating in relation to historic documents as I also held two other senior roles after my departure from The Society. I would be concerned that I might very well come up with answers that do not apply to my time at the Haemophilia Society but to subsequent employment.

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].

55. I have no recollection in relation to the response to this question. I cannot recall when or whether the Terms of Reference came into force.

On 29 March 1993, Dr Elizabeth Mayne wrote to you raising concerns about how the Medical Advisory Panel was operating [HSOC0010922]. Please explain what happened in relation to these concerns and how, if at all, the Panel changed how it worked.

56. Looking at this document I recognise some of the handwriting on the first page as mine saying "*copy to Alan Tanner, Ken Milne, Chair of the Project Group, and Graham Barker, for discussion and comment*" on 2 April 1993. I also ask for the original to be returned to me for reply. I believe the writing on the second page is that of Graham Barker. Unfortunately, I cannot understand his writing. Whilst I recognised this correspondence when I saw it, unfortunately, I do not have any independent recall of its context. Reading the correspondence at this stage it implies that the review of 1991 was not a success, however, I do not have any specific recall in relation to these events.

3.1.2 The Blood Products Sub-Committee

Please set out your involvement with the Blood Products Sub-Committee. In particular, please respond to the following questions to the best of your knowledge:

- **a. What was the role and function of the Blood Products Sub-Committee? When and why was it formed?**
- **b. Over what period of time was the Blood Products Sub-Committee in existence? When and why did it stop meeting?**
- **c. How often did the Blood Products Sub-Committee meet?**
- **d. Who were the members of the Blood Products Sub-Committee? How were members selected to join the Sub-Committee? What criteria, if any, were used?**
- **e. What sources did the Blood Products Sub-Committee rely on to produce its discussions and reports?**

f. **Please explain the relationship between the Medical Advisory Panel and the Blood Products Sub-Committee. To what extent were comments sought from the Medical Advisory Panel before the reports and/or discussion documents from the Sub-Committee were produced and/or disseminated? [HSOC0029467_003, page 2; HSOC0029476_042, page 4]. To what extent (if any) were any other medical professions consulted in the preparation of reports from the Blood Products Sub-Committee?**

g. **To what extent, if at all, did the Haemophilia Society rely on findings or conclusions from the Blood Products Sub-Committee to form its policies?**

h. **To what extent did the Haemophilia Society verify the accuracy of reports and discussion documents produced by the Blood Products Sub-Committee? If so, please provide details.**

i. **How were the reports prepared by the Blood Products Sub-Committee disseminated (if at all)? To whom were they sent? Were the reports provided to the Government or individuals in public office? If so, please provide details.**

j. **What was the nature of the relationship between the Blood Products Sub-Committee and Elstree Blood Products Laboratory ("BPL")? What role did the Blood Products Sub-Committee play in BPL's policy decision making, if any? How (if at all) did this relationship change over the course of your tenure? [HSOC0019504, page 6].**

k. **A review of the Society's policies was apparently undertaken by the Sub-Committee and set out in a report dated 9 January 1984 [PRSE0000851]. This report was, "*conducted against a background of medical advice having been obtained from an appropriate qualified doctor ... the source material listed as justifying the view expressed in that report came predominantly from articles written by members of the medical profession*". Please address the following matters:**

i. Which medical professionals provided the "background of medical advice"?

ii. How was this medical advice sought?

iii. How was this medical advice recorded?

iv. Who decided which articles would be considered in determining the view of the Sub-Committee?

v. How were the views of different articles weighed by the Sub-Committee? In particular, which members of the Sub-Committee had medical experience to undertake that weighing exercise?

vi. It is said that the views came "predominantly" from articles. How else were views formed? On what material were such views based?

l The Blood Products Sub-Committee reported on new commercial products, such as Monoclate from Armour Pharmaceuticals [HSOC0019923_020, page 2].

i. What information did the Sub-Committee receive about these products from pharmaceutical representatives in advance of their release?

ii. Did the Blood Products Sub-Committee investigate the safety of commercial blood products? If so, where was the information concerning the safety of these products sourced?

iii. Was the Medical Advisor Panel involved in any discussions about, or in the evaluation of, the information that was gathered and/or disseminated by the Sub-Committee in relation to the safety of commercial products?

iv. Was the information that was reported to the Council of the Society disseminated? If so, please set out to whom it was provided.

57. This is a very detailed question, and unfortunately, I have very little recall of assistance to the Inquiry's work. It is likely that I would have had a part to play in the Sub-Committee but I have no detailed recall whatsoever after the passage of time. Generally speaking, all Sub-Committees would be created by the Executive Committee, and a member of the Executive Committee would be appointed as Chair of the relevant Sub-Committee. The Chair of that Sub-Committee would then recruit other people to serve with that person on the relevant Sub-Committee, and a member of staff would service the Committee. Nine times out of ten, I suppose, that would have been me.

58. I have been taken to various documents referred to within this question, however, they unfortunately do not jog my memory. Having looked at some of the documentation I can also see that I raised certain questions, for example, in the minutes of the Executive Committee dated 8 November 1984 it is recorded "*in reply to a question from the Co-ordinator, the Executive Committee confirmed that there was no medical evidence available to show that UK product[s] were in any way 'safer' than imported ones, particularly from hepatitis or AIDS* risk" [WITN3429015/HSOC0029476_042]. It is likely that in the event I had any queries, I would have raised them at the Sub-Committee meetings. My role was to seek clarity and give others the opportunity to respond. This, however, did not stop me from raising clarifying issues should I perceive confusion.

59. From memory, the Blood Products Sub-Committee was exactly that. It was concerned with issues arising from blood products. Its remit was to look at the safety, the efficacy and, indeed, the questions around self-sufficiency, because that was also happening around this time. It was at around this time, that I have a very vivid recollection of going to meet Dr Gerrard Vaughan of the Department of Health. When we arrived he was effusive and assured us that the door he knew we had come to knock on was already open and need not be pushed too hard. We were informed that decisions had already been made to upgrade the facilities at BPL, and this came as a major shock to us at the time. We went in

prepared to go all guns blazing, I believe this was potentially around 1982, and we were astounded. Of course, it became clear as history unfolded that the Department of Health were already aware, at that time, that there was a potential for a major crisis with blood products, therefore, they put their foot on the accelerator to achieve self-sufficiency at as early a date as was possible. However, there was nothing said during that meeting about the potential risks of imported blood products or what was later called HIV.

60. I believe that the Blood Products Sub-Committee was in existence in 1981 when I first joined the Society and continued in existence throughout my time at the Society. I cannot recall whether it had regularly decided meeting dates, however, I believe it would have been as and when. I do not recall a membership of the Blood Products Sub-Committee, however, I recall that the late Ken Milne was always a member.

61. I cannot be certain of the sources that the Blood Products Sub-Committee relied on to produce its discussions or reports. Given the passage of time, I would have expected it to involve going out and talking to the relevant people and Centre Directors, possibly the pharmaceutical companies themselves, certainly BPL to find out what was going on or what wasn't going on in relation to self-sufficiency. There was most certainly an investigative role associated with the work of the Blood Products Sub-Committee.

62. I do not believe that there was any direct link between the Medical Advisory Panel and the Blood Products Sub-Committee. I believe, however, that Ken Milne, was somebody who had his eye on matters generally, and would have, at times, attended both the Medical Advisory Panel and the Blood Products Sub-Committee.

63. Given the limitations (in terms of staffing and facilities) of The Society and the work it was trying to achieve at the time, it relied extensively on the work of the

Blood Products Sub-Committee. As stated elsewhere in this witness statement, The Haemophilia Society was a very small fledgling organisation, and it was not set up with a massive armoury of administrative backup. So its ability to verify the accuracy of reports and discussion documents produced by the Blood Products Sub-Committee, or any other committee for that matter, was extremely limited. The Society had to trust those from whom it was receiving advice.

64. Anything decided upon or discussed at the Blood Products Sub-Committee would be reported back to the Board, the Executive Committee. In the event that anything was published, that was really down to the editor of publications. The Blood Products Sub-Committee would never report directly to Government, for example. Everything would always go through the Executive Committee. If the Executive Committee wanted something raised with the Department of Health it would be raised through our normal communication channels.

65. I would describe the relationship between the Blood Products Sub-Committee and BPL as the same as the relationship with any other pharmaceutical company; professional and enquiring.

66. I have been asked to consider the document WITN3429016/HSOC0019504, which is The Society's annual report of 1985. I have no further comments or observations in relation to that document. I feel it is a factual account of what happened at the time.

67. I have also been asked to consider the document WITN3429017/PRSE0000851. I had no input whatsoever into the drafting of that letter. As stated above, I have no recollection of the review of The Society's policy that was referred to that took place in January 1984.

68. In relation to the report by the Blood Products Sub-Committee on new commercial products, such as Monoclate from Armour Pharmaceuticals, I cannot recall what

information the sub-committee received about these products. The safety of commercial blood products is entirely a matter for the regulatory authorities. The Society was not a massive organisation with its own laboratories in order to conduct such tests, we had to rely on what we were told. There was nothing that the sub-committee could do in order to investigate the safety of products, save for asking for advice from its Medical Advisory Panel. Whilst I cannot recall the specifics of this instance, I believe that any information that The Society received, the Centre Directors would have also received and it would have come up at a meeting at some stage.

69. If The Society felt that any information needed to be disseminated it would be shared with the Council, that consisted of representatives of the local groups. It was then for the Council members to distribute the information to their local group as they thought best. From recollection, however, generally they would wait for the printed word to arrive. If the Council met and then reported up to the Executive Committee, and they felt it was necessary, they would then submit it or include it within the next Bulletin publication, for example. If the Council felt there was something that their local group needed to be aware of more urgently, before any further dissemination from The Society as a whole, it would then share that with its own local members.

70. Again, this is another instance of The Society being a very small organisation. It did not have the resources to conduct full investigations into products. The Society had its Medical Advisory Panel, and its various sub-committees, however it must be borne in mind, that the majority of these individuals were volunteering.

3.1.3 Hepatitis Project Team/Task Group

It appears that in September 1991 the 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 may also be of assistance].

71. I have no recollection whatsoever of the Project Team. I note that I am shown as in attendance at one of the meetings in September 1993, however, I cannot imagine why I was involved in this at all. The documents that I have been referred to in order to assist in responding to this question, are all to and from Graham Barker. I suspect that there would have been much more to this story than these documents that I have been referred to, but again, unfortunately, I have got little recall of the events of that time.

3.2 Interaction with Other Organisations

Please describe the relationship between the Haemophilia Society and the UK Haemophilia Centre Directors Organisation ("UKHCDO").

72. The relationship between the Society and the UKHCDO was, on the whole, respectful and cooperative. As stated elsewhere in this witness statement, all members of The Society's Medical Advisory Panel were also on the UKHCDO. There was regular contact between The Society and the UKHCDO, there was an ease of contact and an appreciation of each other's roles.

What was your role and involvement with the UKHCDO? What was the function and purpose of the Haemophilia Society's committee members attending the Regional Meetings of UK Haemophilia Centre Directors in the 1980s and 1990s?

73. My role was minimal and would have included reporting back along with a member of the Executive Committee who would also have been in attendance. Attendance by the Executive Committee members was of really great importance, because it was they who were interrogating the physicians about their role and their decisions and their view of the future.

At a meeting of the AIDS group of the Haemophilia Centre Directors Organisation on 2 July 1985 [HCDO0000271_066], a question arose as to whether an agreement made by the Society in 1968 to patient's names being entered into the Oxford Secretariat's National Computer was "*blanket approval on behalf of all patients*". What did you understand the agreement in 1968 to have been related to? What did you understand to be the issue that had arisen in 1986? And how was this issue resolved?

74. Having considered this document, it is clear that I was not in attendance at this meeting. As I was not at this meeting I cannot recall details that were discussed. In addition, I was unaware of the agreement from 1968, as far as I can recall. This was obviously before my time at The Society.

In a report dated 22 July 1993, you recorded a concern that had been raised in a meeting with (it seems) medical practitioners [HSOC0003288]. This concern was about coercion of patients to participate in research studies without being aware of it. The matter was referred to the chair of the relevant committee of the UKHCDO. Please explain what the concern was, the basis of that concern and what happened after the matter was referred back to the UKHCDO committee.

75. I have no recall of this meeting, and have no recall of my concerns at that time.

In the Bulletin, Edition 32, No. 2 1982, Mr Prothero described the Society as, "*a unique combination of lay and medical skills ... The medical side basically comprises our Medical Advisory Panel and our links with other medical and para-medical staff*" [HSOC0022901]. Do you agree that this was an accurate description of the Society? Who did you understand Mr Prothero to be referring to when he referred to "other medical and para-medical staff" with whom the Society had links?

76. Having considered the document referred to in this question, it would be hard to disagree with this statement as made in 1982. In relation to "*other medical and para-medical staff*", I suspect Mr Prothero was referring to Centre Directors, haemophilia nurses, the haemophilia social workers, physiotherapists, and others that assisted with the care of those who lived with haemophilia.

What was the relationship between the Haemophilia Society and the British Association of Social Workers ("BASW")? What interactions took place between the two organisations? How did this develop over time?

77. The relationship was with the Haemophilia Special Interest Group of BASW. The social workers were often involved in our regional meetings, our annual meetings. It was a good working relationship. The relationship was established because we all had the same focus, which was the patient who had haemophilia. The relationship evolved naturally over time and was established before I joined The Society.

What was the relationship between the Haemophilia Society and the Haemophilia Nurses' Association? What interactions took place between the two organisations? How did this develop over time?

78. The relationship between The Haemophilia Society and the Haemophilia Nurses' Association was very similar to that with the British Association of Social Workers. Both establishments had the common interest of ensuring that people with haemophilia received the most appropriate treatment. There is an article in the Group Seminar Proceedings published in December 1981 by Sister Maureen Fearns which confirms that the Haemophilia Nurses' Association was only established on 13 March 1981 [WITN3429002/PRSE0003316].

Section 4 – Communication and Dissemination of Information by the Society

4.1 Knowledge of risk

When you began to work for the Society in 1981:

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?**
b. **What, to the best of your knowledge, was known and understood about the risks of the transmission of hepatitis from blood and blood products by others within the Society? What were the sources of their knowledge? How did their knowledge and understanding develop over time?**

79. At this time, I was engaged as an administrator, the Co-ordinator, for The Society, and had no medical background. One could not be in the environment without becoming aware of the concerns and the problems of people with haemophilia and the evolving problems as they developed. When I joined The Society I had no background knowledge of haemophilia and its complications. I did not learn in a vacuum, I learnt by meeting people who had haemophilia in all its forms, including most members of the Board.

80. I would also be invited by Centre Directors, by nurses and by social workers to take part in their clinics with the consent of the patient. As a result of this interaction I had a pretty thorough grounding and understanding and, in fact, many people gave me the wonderful undeserved title of being an honorary person with haemophilia.

81. As someone with an ear to the ground, I rapidly became aware of the risk of transmission of hepatitis from blood and blood products from reading generally and listening to what doctors and nurses had to say. It was very incomplete knowledge at the time. Hepatitis C was known as a Non-A Non-B Hepatitis in those days and it was not terribly specific. There was no diagnosis, no treatment,

and on the whole it was because of the lack of scientific information that it was regarded as something that went with the use of blood products and something that was not all that serious in the early days. I believe that in my early days at The Society, there were references to the potential risk of hepatitis in pooled blood, but it was believed to be a mild form of the virus. It was acknowledged that it was not Hepatitis B, but nobody really knew what it was.

82. I have been asked what was known and understood about the risk of transmission of hepatitis from blood and blood products by others within The Society. Most of them were living with the lifelong condition themselves. And it is impossible to have a lifelong condition without getting to know a great deal about it and forging trusting relationships with your doctors and nurses, so they knew a great deal more than I would ever know about it. As things developed, the very real stresses that came with the uncertainty became clear. They were considering the potential impact on their families and their intimate relationships and I was very much on a learning curve courtesy of the people with haemophilia with whom I worked.

When and how did you first become aware that there might be an association between AIDS and the use of blood products?

a. What if any steps did you and your colleagues within the Society take in light of your awareness of this association?

83. I believe it would have been towards the end of 1982 or the beginning of 1983 that we began to develop our knowledge of a potential association between AIDS and the use of blood products. From recollection, I think the record will show somewhere in minutes that Clive Knight, who was a trustee, and I had quite a tough battle persuading the Executive Committee that this was a live issue, and an issue that would affect people with haemophilia in the United Kingdom, and the response from the Executive Committee along the way was "*well, of course, it will not happen here*". It was imagined that the United Kingdom was different

to the United States. We had the discussion that this was likely to affect people in the United Kingdom. Clive and I were trying to say that there was evidence that contaminated donations were being made in the United States and that this would, in turn, affect people in the UK. Very soon thereafter the first deaths in haemophilia were being recorded in the United States. This was very much in the early days of my time at The Society.

4.2 Publications

Please detail the publications that the Haemophilia Society sent out to its membership from the 1970s onwards. Please describe the frequency with which each type of publication was disseminated and whether they were all sent out to all members of the Society. If this changed over time please detail when and why. The Inquiry is aware of:

a. The Bulletin;

b. Group Seminar Proceedings;

c. Haemofact; and

d. C Issues.

84. I can only provide a response in relation to 1981 onwards. My recollection certainly includes the Bulletin, which became a professionally printed publication. Before that it was duplicated. In my time the Bulletin was quarterly. The Group Seminar Proceedings publication was published as and when. Likewise, Haemofact was published as and when. I have no recall of C Issues and whether this was sent out during my time. The Society also published its annual reports.

85. The Haemofact was first published in 1983. This was in response to the Mail on Sunday article on 1 May 1983. The Haemofact was only a couple of pages in length and that initial, first, publication was essentially drafted by Professor Bloom. After this first publication, Clive Knight suggested that it became a series thereafter. I once heard the Haemofact being described as the most unread

publication that we ever sent out. It often contained bad news and as such the membership tried to avoid it.

86. Contained within the papers that have been provided with me to assist with the preparation of this Rule 9, I have also seen a publication called The Update. The document reference for this document is WITN3429018/HCDO0000276_018. I could not recall this publication until I had seen this document in the bundle of documents provided to me. This update is the number two update from April 1989. The Update is described in document WITN3429019/PRSE0004704 as "*A single sheet publication prepared by the Haemophilia Society was prepared from about 1987 onwards. There were several issues each year. Most of the content was about Haemophilia Society activities including the campaign for those infected by HIV for financial help from the government*".

87. I am aware that a number of clinicians have provided evidence to the Inquiry in respect of what information they provided to their patients regarding the risks associated with blood products. A number of clinicians have stated that in addition to any information they provided, the patients had information disseminated by The Society. Whilst it is accepted that The Society posted copies of its publications to most of the centres, it was never the intention that this information would replace the medical advice of the clinicians. I believe that a number of the publications stated such and recommended that individuals refer any queries or concerns to their Haemophilia Centres. All publications were designed to be informative and were never intended to substitute medical advice. The Haemofact had a paragraph similar to the following in each publication "*Please continue to discuss your personal position with your Centre Director. While we would urge you to remain on treatment, the final decision lies with you and your medical advisers. Their advice must always be given priority over any general advice which we may give*".

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).

88. The Medical Advisory Panel would have had no involvement in selecting material for The Haemophilia Society's publications. The members of the Medical Advisory Panel were often asked to draft articles but the decisions in relation to what would be included within each publication was down to the Editor of Publications. The Editor of Publications was always a member of the Board, a trustee.

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).

89. As far as I recall, the pharmaceutical companies did not assist in proposing and/or editing any articles whatsoever in The Society publications. They never had adverts either within the publications as this was against the code of practice of the Royal Pharmaceutical Society. At regional days and AGMs, all of the pharmaceutical companies had the opportunity to have a stand but not to promote their products. They could be there to answer questions from people about their product, but there was to be no direct promotion and advertising the products. They would often provide keyrings or a pen or something like that. As far as I recall, however, they were never allowed to address meetings or such like.

90. The pharmaceutical companies sometimes sponsored publications, and this was confirmed by including a short paragraph in the publication to state that the publication had been sponsored by a particular pharmaceutical company. That

was not advertising their products. All sponsorship was always offered to all pharmaceutical companies on an even-handed basis. It was up to each company to determine as to whether they wanted to provide any sponsorship, and if so, how much.

4.2.1 The Bulletin

Please explain how the Bulletin was made available to members and the wider haemophiliac community. What was the Haemophilia Society's knowledge of the extent of the Bulletin's reach within the haemophiliac community?

91. The Bulletin was made available by post to every member of The Society. The task of posting the Bulletin to the membership was extremely difficult. Each address was initially typed on a typewriter with the use of an addressograph. The addresses were always in the addressograph in alphabetical order, however this would often go wrong when going through the address protocol process.

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

92. During my time, I arranged for copies of the Bulletin to be mailed to each and every haemophilia centre. The number of patients at a Centre, would determine how many copies of the Bulletin they would receive. The Royal Free in London would have quite a sizeable bundle, whereas somewhere like Mark Winter's Centre in Margate, would get a much smaller bundle, because it did not have as many patients. Most healthcare professionals would in any event also receive their own copy as they were also on our mailing list. That would be the Centre Directors, the nurses, the social workers and the physiotherapists, for example.

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

93. The Editor of Publications had the frontline responsibility for editing and selecting material for the Bulletin. The Editor of Publications was answerable to the Executive Committee, and as stated above, would be a Trustee. During my time at The Society Clive Knight and Andy Cowe held the role of editor at separate times.

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

94. It would be very rare for members to be proactive and offer any input to The Society publications. As far as I am aware, the Editor of Publications would always decide what was included in each publication. Ultimately, every edition went to the Chairman to be signed off. As stated above, communication was not as easy as it is these days during my time at The Society. The publications would be pulled together and shared by the Editor of Publications with the Chair of The Society. The Chair would then consider the publication and sign it off. In the event that an article would contain scientific information and/or opinions provided by the medical profession, the contributors would themselves be qualified to make such a decision. As a small voluntary organisation comprising people with no clinical qualifications, we trusted the members of the Medical Advisory Panel to provide clinical information that was accurate.

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

95. As stated above, the Medical Advisory Panel were themselves medically qualified, as such The Society relied heavily on them for the accuracy of any publications. The Society trusted the members of the Medical Advisory Panel and we had no reason to double check the clinical information provided; in any event, we lacked the clinical expertise to do so. The Society would turn to the Medical Advisory Panel for advice and would consider that advice as the best available advice at that stage.

4.2.2 Haemofact

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

96. The Editor of Publications, the Editorial Board and the Executive Committee were responsible for editing and selecting material for the Haemofact. Material contained within the Haemofact was often drafted by a member of the Medical Advisory Panel. Where a member of the Medical Advisory Panel wrote a piece for the Haemofact, their name would be published along with the piece.

When did the Haemofact publication come into being? What was its primary purpose? Over what period was it produced? Who was the target audience of the publication? How was it made available to members and others?

97. As stated above, the first Haemofact was published in May 1983, in response to the Mail on Sunday article on 1 May 1983. It was initially made available by post to all members because the Board did not know who was, or who was not, HIV positive. Haemofact focused specifically on the HIV development. It came into being to keep members informed about the developing crisis.

4.3.2 Chronological publications

Please consider the letter from Rev Alan J. Tanner dated 4 May 1983 [DHSC0001228]:

a. **Please explain why the letter was sent out on that date?**
b. **Had the Haemophilia Society sought and/or obtained any advice in relation to AIDS before this date? If so please set out who that advice was sought from, what advice was obtained and what steps the Haemophilia Society took having received such advice.**
c. **Were the contents of the 4 May 1983 letter discussed and/or verified as accurate with any members of the Medical Advisory Panel, save for Professor Bloom? If so, please set out who it was discussed with and what their view was. If it was not, please explain why not.**

98. That letter was drafted following the Mail on Sunday article of the previous day. The Society felt that it needed to send something to its members to allay their concerns. I believe it likely that The Society would have sought advice in relation to AIDS before this date. Had we sought any advice, it would have been from the Department of Health or the Medical Advisory Panel. I think it is fair to say, that we were not surprised by the article as such, we were surprised by the content of the article, which was inaccurate. The article stated that Switzerland could meet all of the UK's needs for pure Factor 8. In reality, Switzerland could hardly meet its own needs, never mind the needs of the UK as well. I believe, at a later date, there was a subsequent Press Council apology for the inaccuracies within that article. I know that we at The Society were in touch with the Press Council about it and they were unhappy at the time.

99. The conversations that The Society had previously had with the Department of Health, the Medical Advisory Panel and the UKHCDO were specifically in relation to the advice that should be provided to members as to whether AIDS would be a problem or not. It was scenario-setting advice really, so that we could know what to expect and anticipate. Of course, we now know that Professor Bloom

was heavily influenced in what he wrote that day by a letter he had received from the health authorities a short while before that.

100. A number of years ago I was asked to participate in a Panorama television programme in relation to the contaminated blood scandal. As part of that, I was shown a very heavily redacted letter written to Professor Bloom appearing to warn him of the potential risk of AIDS. I have never received a copy of this letter and I believe this is something that the Inquiry should look into. Having considered this letter briefly as part of the Panorama documentary, I believe that much of what he shared in The Society update of May 1983 was almost literally copied from that letter. Time was of the essence in getting our letter of 4 May published and disseminated to members. The telephone at The Society was ringing off the wall that Monday morning, to the extent that I could hardly get that letter published. At the time of publication, the staff of The Society consisted of me and one secretary, Irene Hawkins (now Love).

101. The content of the Bloom letter was not discussed and/or verified as accurate with any other members of the Medical Advisory Panel, as far as I am aware; we simply did not have the time to do that. In any event, as stated elsewhere in this statement, that was not the practice at the time. In relation to urgent matters, it was unheard-of for us to double check, or verify, advice received from the Medical Advisory Panel, particularly from Professor Bloom, as he was regarded as an expert in his field. In addition, we did not have the benefit of modern communications. However, as identified above, we did follow this up with the Medical Advisory Panel and also Professor Bloom himself a short while later. At the seventeenth meeting of the Haemophilia Reference Centre Directors on 19 September 1983 [WITN3429020/PRSE0003196], it is noted " *Mr. Watters of the Haemophilia Society had asked Professor Bloom for an up-date of the AIDS circular which was sent out in May for distribution to all of the Society's members. Professor Bloom read through the document he had prepared for the Society and this was approved by the Reference Centre Directors"*. Therefore, whilst wider

advice was not sought due to the urgency of the situation, no members of the Haemophilia Reference Centre Directors disagreed with the advice provided by Professor Bloom.

In May 1983, the Haemophilia Society Bulletin 1983, included an article entitled, "AIDS and haemophilia" [PRSE0004120, page 12]. The author interviews Dr Peter Kernoff, Director of the Haemophilia Centre at the Royal Free Hospital in London. Dr Kernoff claims that AIDS is an "*unusual disease*" and that he "*expects it to remain a rare disease*". He also claims the link between AIDS and haemophilia is "*very tenuous*" and that the "*idea that there is an epidemic of AIDS amongst haemophiliacs is ludicrous*". He states that "*the benefits [of treatment with concentrates] far outweigh the possible risks*" and that he sees "*no reason to make any change from current practice*". To the best of your knowledge, how (if at all) did the Haemophilia Society verify the accuracy of the statements made by Dr Peter Kernoff in May 1983? 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.

102. It was up to the editor to make the decision about what went into the Bulletin. The interview would have been conducted by Clive Knight, I know that, as he was Editor of Publications. Once the final draft was available, a copy would have been submitted to the Board for approval. Dr Kernoff was an internationally recognised and respected authority on haemophilia, as such, The Society would not go to the expense, both time and money, of verifying what he was saying. He was also a member of the Medical Advisory Panel.

The Bulletin Edition 32, No. 1, 1984 published an article entitled "Blood Products" by Ken E Milne. In the article, Mr Milne states: "*We have no evidence as yet [as] to whether AIDS may be acquired more readily from commercial*

***Factor VIII than from the NHS product but, of course, if AIDS becomes established in the UK then NHS blood and plasma supplies are just as likely to transmit AIDS as commercial concentrates. All things considered, haemophiliacs have no reason to be worried about using commercial concentrates*" [PRSE0000922]. To the best of your knowledge, how (if at all) did the Haemophilia Society verify the statements made by Mr Milne? 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.**

103. Mr Milne was chair of the Blood Products Sub-Committee and Assistant Editor of Publications, as such it would be felt that he was adequately qualified to write such an article, based on his knowledge and his consultation with experts in the field. The message he was delivering, was precisely in line with what the Department of Health were saying.

In a press release dated 20 December 1984, the Society stated that, despite news that Scottish Factor VIII had been found to be contaminated with HTLV-III virus, "*we remain of the opinion that treatment ... is the first priority for anyone with haemophilia, based on the firm conviction that haemophilia, itself, is more dangerous than AIDS*" [DHSC0000684]. Please explain how the Society came to this "*firm conviction*"? Did the Society obtain advice in relation to this position from any medical professional? If so, please set out who that was, when the advice was sought and obtained, what the advice was and how that advice was verified as accurate.

104. From recollection, this was a continuation of the advice given by the Government and passed to us by Professor Bloom. They were tough times, parents of young children and indeed many younger adults certainly had no idea what it was like not to treat haemophilia and the risks that would involve. The risk of things like

intercranial bleeds and so on were a real risk. The average age of people with haemophilia rose from 20 or the mid-20s, to almost the national average, as a result of using Factor VIII. Factor VIII had been considered a 'miracle drug' that improved the life opportunities of many and it was a particular tragedy that the eventual outcome was so far from 'miraculous'. The pain and anguish of those involved will stay with me as long as I live.

In December 1985, the Bulletin published an article, entitled "As Construction at Elstree keeps to schedule: UK Self-Sufficiency confirmed for 1986" [PRSE0001088]. The author quotes you as saying: "*And although the press has been dramatizing the AIDS problem and the risk of imported blood coming into this country, I think it is very important not to forget that without the imported product the quality of those who need Factor VIII and Factor IX would have been much poorer.*" Please can you explain your thinking behind this statement and elaborate on it. How and on what basis did you and/or the Haemophilia Society conclude that the media was "*dramatizing the AIDS problem*" and the risk of imported blood products during the relevant period?

105. As stated in response to the preceding question, the average life expectation was increased by the use of blood products. As a result of this, people with haemophilia were able to enjoy better employment and were better at functioning in society. All of that came about as a result of using Factor concentrates. Because the UK Government failed to meet David Owen's pledge to become self-sufficient by the late-'70s, this meant that we had to import vast amounts of Factor VIII, which proved at too late a date to come from dubious backgrounds.

106. In relation to the comment of "*dramatizing the AIDS problem*", I reached the conclusion that the press and the media were dramatising the reality based on the number of calls I had received from anxious parents whose child had haemophilia, possibly not even HIV positive, and the fact that they were being stopped from going to school because of protests from other parents. Fears were

also expressed by teachers, clergy and it felt like everybody else in the country as well as large numbers of abusive telephone calls. The overreaction of teachers, parents, and the public generally to the potential risk of HIV infection, was exaggerated by the media. I did not intend this comment to be in the context of dramatising the AIDS problem for those with haemophilia, I meant it in the context of the wider population and the media reaction, which detracted greatly from our work in serving the needs of people with haemophilia so tragically coping with life changing and life limiting situations.

107. Documents show, a little later in 1987 that "*a number of very nasty phone calls had been received at the national office along with some 'hate mail' – anonymous, of course"* [WITN3429021/HSOC0019923_020].

In a document entitled "A summary of contents and personal observations on Counsel's opinion" dated 23 January 1987, you noted "*Those statements also serve to hasten the day when it will be necessary for us as a Society to get a responsible and authoritative source to make some form of public statement about the prospects for people with haemophilia. Every indication which I hear, apart from a very few, indicate that the likely progression from HIV ab+ to frank AIDS in haemophilia is likely to be remarkably low. However we do need and expert to say just that!!*". A handwritten note is then added at the end "*and strongly*" [HSOC0029599]. Please explain the following points:

a. **For whom were you writing this document, and why was it written?**
b. **Who was the document distributed to?**
c. **What was the basis for your statement that the likely progression to frank AIDS was likely to be remarkably low? In other words, please explain who had told you this and/or provide the details of any written documents you relied on at the time.**
d. **Why did you say that an expert needed to say this publicly?**

e. Did the Haemophilia Society ask an expert to publicly state this position? If so, when did they do so, who was the expert and who was the information provided to?

108. There are a few points to note in relation to this document. This is clearly an internal memorandum that only went to the Chairman of The Society. My recollection of this document at this point in time is limited, however, I note that it seeks permission to share this information with the rest of the Executive Committee. The record that I have been shown, does not show whether that ever happened. The Chairman's say was final on any documents that were or were not circulated.

109. At this point in time, I would guess that this document was written to save the Chairman's time in reading the entirety of Counsel's opinion. I can no longer recall what the basis of my statement was. I can only suggest that that was contained within Counsel's opinion. However, time proved me and those I quoted wrong, in any case. Knowledge of the meaning of antibody positive was not precise at the time, no more than it is now, in October 2020, with Covid-19. There was huge controversy at the time about the meaning of antibody positive, what it meant and how long it meant and so forth.

110. I can also only assume that I said an expert was needed to say this publicly in order to quell some of the hysteria and the fears that were about at that time. As far as I can recall, The Society did not ask an expert to publicly state this position.

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

source of the factual information needed to prepare the pamphlets…". **Please comment on the accuracy of Professor Bloom's statement.**

111. All I can say in response to this is that this most certainly does not coincide with my recall, and unfortunately Professor Bloom is no longer with us to contradict them either. However, the content of the Haemofacts themselves suggest otherwise I would therefore say that Professor Bloom's comments are inaccurate. I recall having significant correspondence with Professor Bloom and other members of the Medical Advisory Panel during my tenure at The Society.

In your evidence to the Penrose Inquiry, you stated that, "*I think HIV and AIDS left all of us much wiser than we were before HIV and AIDS, and there were cries in the distance, in the background, that not all haemophilia clinicians felt the way that the view was being represented to us*." [PRSE0006087, page 124, paragraphs 9-13]. Please elaborate on this statement. Did some haemophilia clinicians feel that their views on HIV and AIDS were not being communicated to the Haemophilia Society? Did some haemophilia clinicians feel that their views on HIV and AIDS were not being represented by the Haemophilia Society to its members? When and how did you come to know these views? Once you were aware of those alternative views, what did you do about that? If you have already answered this question in prior sections of your response, please identify the paragraph number(s).

112. Given the passage of time, I have no distinct recall of the queries raised in this question. However, I do recall that younger, newer Centre Directors held a variety of views and hence we sought to bring younger Centre Directors onto the Medical Advisory Panel. From memory, there were people like Matthew Helbert, Andrew Jennery and others. I became aware of these views through phone calls and casual conversations. As far as I recall there was never a formal representation about it. When we became aware of these views, that contributed

towards the decision to attempt to get younger individuals involved in the Medical Advisory Panel.

Considering your answer to question 55, did the Haemophilia Society know of haemophilia clinicians who felt that their views on imported blood products were not being represented or communicated to members of the Haemophilia Society? Please provide details, identifying clinicians where possible and the issues they raised. Please explain when and how you came to know of these alternative views and, once you were aware of them, what you did about that.

113. This is a very specific, detailed question and unfortunately it is detail that I do not recall given the passage of time.

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 Simon Taylor, Society Vice Chairman, 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 material 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.

114. As previously stated, the Editor of Publications was responsible for all publications. This article appears to have been written by a Vice-Chairman of the Society, and the Executive Committee, through the Chairman, would have approved all publications.

Please consider the following documents:

a. **HAEMOFACT – AIDS no.2, 22 September 1983 [PRSE0000088]**
b. **HAEMOFACT – AIDS no.3, 11 May 1984 [DHSC0001264]**
c. **HAEMOFACT – AIDS no.4, 24 September 1984 [DHSC0001265]**

d. HAEMOFACT – AIDS no.5, 3 December 1984 [DHSC0001266]

e. HAEMOFACT – AIDS no.6, 22 April 1985 [DHSC0001267]

f. HAEMOFACT – AIDS no.7, 22 May 1985 [DHSC0001268]

Please answer the following questions:

g. To what extent (if at all) were medical professionals relied upon to produce the advice and opinions in these documents? [BPLL0001351_076], [BPLL0001351_084] and [BPLL0001351_089] may also be of assistance.

h. Who provided that advice?

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

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

k. What was their advice in relation to each of the articles above?

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

m. Where the documents directly quote a member of the Medical Advisory Panel, 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 was it not followed.

115. The content of all publications was within the remit of the editor of publications and the Executive Committee, through the Chairman of the Trustees. Taking each of the Haemofacts in turn:

a. Haemofact no. 2 on 22 September 1983, repeats the Bloom letter of May 1983.

b. Haemofact – AIDS no. 3 of 11 May 1984, is signed off by Christine Lee, the Senior Registrar, at the Katharine Dormandy Haemophilia Centre. She was also a member of the Medial Advisory Panel.
c. Haemofact – AIDS no. 4, 24 September 1984 was written by Peter Kernoff, again, another medical professional and a member of the Medical Advisory Panel.
d. Haemofacts no. 5 and 6 do not appear to convey any medical advice. Both of which contain campaign information.
e. Haemofact 8 no. 7 22 May 1985, is a reproduction of the April 1985 AIDS Centre News published by the World Haemophilia AIDS Centre in Los Angeles. The Director of the World Haemophilia AIDS Centre is Dr Shelby Dietrich, again an internationally renowned authority in Haemophilia and AIDS.

116. It would always be the editor who decided which medial professions should be approached. The editor would be the one to seek such advice, and the professionals would provide the advice directly to the editor.

117. In relation to the documents referred to in part g of this question, it can be seen that some correspondence went from me and some went from Reverend Tanner. However, they were not specifically asking for advice in relation to the Haemofact. If these individuals provided any advice it was contained within the articles, because they were essentially the articles. It is anticipated that the editor may have edited some of these, however, quotes were always used to directly quote the Medical Advisory Panel. The Society did not have the luxury of time in order to obtain advice from other medical professionals to verify advice it received from the Medical Advisory Panel. It relied very heavily on the advice it received from its Medical Advisory Panel. I would like to take the opportunity to again, emphasise that The Society was a very small establishment. The Society was strapped for both time and resources.

118. As referred to at paragraph 87 above, The Society regularly reminded its members to discuss their treatment plans with their Centre Directors. Haemofact No. 2 stated "*…please continue to discuss your personal position with your entre Director. While we would urge you to remain on treatment the final decision lies with you and your medical adviser. Their advice must always be given priority over any general advice which we may give*". Haemofact No. 5 [WITN3429022/DHSC0001266] stated "*If you have any enquiries about your own position you should speak to your Centre Director who will be only too anxious to assist you*".

4.3 Other communication

4.3.1 Communication to members

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

119. I personally spent a considerable amount of time working with the media. I did lots of work on the radio, television, communicating with newspapers and magazines. These communications would be in relation to haemophilia in general, it was a campaign. It would be leaping at every opportunity to transmit the word and raise awareness of haemophilia.

120. We also spent a considerable amount of time progressing matters for members. These events would be structured around the work of The Society, the work of the physicians and the work of nurses. For example, we would arrange weekends for the members that would take place approximately three times a year. Residential weekends may have been once a year but regional days were three or four times a year. We were also developing an effective welfare benefits advice scheme aiding members with applications for various benefits and helping them through the claim process as far as tribunals and

appearances before Social Security Commissioners. We did our best to respond to the needs of the community however humble that may have been.

With regards to Group Seminar Proceedings [for example, PRSE0003316 and PRSE0003079]:

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

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

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

d. What was the purpose of publishing the Proceedings?

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

121. Group Seminar Proceedings were being mailed to all of the membership as part of keeping them informed about what was available at the time. Quite how we found the time to do this, I do not know. The documents referred to me within this question, were the early ones. Both were pre-HIV. I believe there were more of these Group Seminar Proceedings published than I have been referred to, however, I have no actual recall of them. These were all publications that followed a seminar as I referred to above. The aim was to disseminate the knowledge to the wider population other than only to those who attended the actual event. Again, decisions about topics to be discussed at the Group Seminar Proceedings were made by the Executive Committee. I suspect, that there was also a sub-committee. However, I have no distinct recall. As with other Society publications, these would have been sent to the membership and sent to Centre Directors, in exactly the same way as the Bulletin.

In his evidence to the Penrose Inquiry, Chris James, Chief Executive of the Haemophilia Society, stated that, "*the activities of the Society in disseminating information to its members were often spearheaded by haemophilia doctors*" [PRSE0000851, page 3]. Do you agree with this statement? If so, please

provide details identifying doctors where possible and detailing their activities in disseminating information to the Society's members.

122. I agree with Chris's statement, however, unfortunately I have no recall to be able to provide any supporting information of this. I understand that many haematology consultants have provided evidence to the Inquiry that they recommended to patients and people who were newly diagnosed or parents of children newly diagnosed, that they join The Society.

Did the Haemophilia Society receive direct enquiries 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 sources (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.

123. This is a very broad question. The response would also depend on which member of staff was available to answer the telephone. I personally recall handling a large volume and very demanding calls from people with haemophilia. I would never provide specific advice and members were always encouraged to discuss issues with their own haemophilia physician. If we saw repeated similar questions we would sometimes seek permission to go to the Medical Advisory Panel, however, for the majority we would refer them back to their own Centre Director. If there were any difficulties I would possibly say, "*Well, you will be going to the regional centre for a review, raise that question there*".

124. We most certainly did not see ourselves as experts in providing personalised information to individuals. We could only provide generalised information in response to the enquiries.

Prior to 1993, what information and advice did the Haemophilia Society provide to members on the:

a. **Risk of Non-A and 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.**

125. Unfortunately, my recall does not extend to provide detailed answers to these questions. I assume that written material will be available from the Haemophilia Society.

Considering your answer to question 63, 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 63 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.

h. Please consider [BPLL0001351_094], a letter from Professor Bloom to you dated 29 February 1984, in which he observed that "*Hepatitis is now the second commonest cause of death in haemophilia after bleeding. Since the ill effects of liver disease may take 20-20 years [sic] to manifest themselves we may well be in for progressive problems from this disease*". What this advice communicated to members and if so how and when?

126. As stated in response to the above question, unfortunately I cannot recall the detail in respect of the matters listed within this question. In relation to the letter referred to in part h of this question, I believe that the letter would have been passed to Ken Milne and the Blood Products Sub-Committee. It is interesting to note that in this letter in 1984, Prof Bloom states *"I am not quite so complacent about importing American blood products as he*"; this is a distinct change from the advice provided a year earlier.

When the Medical Advisory Panel met on 27 April 1990 [HSOC0010954], it was noted at paragraph 7d that, "*A number of people are known to be Hepatitis C positive from blood tested from stored samples. This brought up the old ethical dilemma of how to inform people of a test result that they have not asked for*". What was your understanding of this situation? What did the Haemophilia Society do in light of this knowledge? Did the Haemophilia Society

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

127. I have no recall of the situation at the time, however I do recall that this was a live issue, that people's serological samples had been subject to testing without their knowledge. I believe that this was also aired as a possible cause for litigation against individual doctors. Unfortunately, that is as much as I can recall.

128. If we, as The Society, had any significant concern in respect of this it would have been communicated to the members through the regular publications. However, around this time, there were many issues being addressed and the significance of this may not have been identified against the other, wider issues.

In the minutes of the Executive Committee, on 14 November 1991 [HSOC0010385] under the subheading 'Hepatitis' it is stated that, "…*the Team had concluded that hepatitis should not be a major concern for the Society. 80% of people infected with HCV and HBV would show no clinical signs and the treatments available were limited; the understanding of the progression of liver disease could only be established through liver biopsies, now considered unethical. The team felt that the Society was in danger of creating concern and worry where they need not exist. Publicity and high profile coverage would be out of proportion to the threat that actually existed.*" Had the Haemophilia Society sought and obtained any advice in relation to Hepatitis C before this date? If so, please set out who that advice was sought from and what advice was obtained. If it was not sought, please explain why not and please set out the basis for the views expressed in the Minutes. 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.

129. Given the passage of time, I cannot recall what was meant by these comments and would be speculating if I were to try to answer the detailed questions asked of me.

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

130. To the best of my recollection, we did nothing specific for healthcare professionals. Our focus was always on our membership.

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*" [underlying added] [HSCO0010277]. 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?

131. I have no recollection of The Society lobbying smaller centres during my tenure at The Society.

It is said in the book 'Blood' by Douglas Star [PRSE0003430, page 3], that you wrote a letter to clinicians in late 1984 or early 1985 saying that "*in ten days we*

were going to contact all our members and tell them to immediately stop using unheated products". **Is this an accurate statement? If so, please explain when the letter was written and to whom it was written. If possible, please provide a copy of the letter. Please explain why the letter was written at that time.**

132. I believe that would be an accurate statement and independent verification should be available in Haemophilia Society files. I have no distinct recall of when the letter was written and to whom it was written, however, I do recall that it was written after heat treated product was available in sufficient quantities to treat all haemophilia patients in the United Kingdom and it was intended to avoid 'cheapskating' by health authorities who would not pay the extra cost. Unfortunately, I no longer have a copy of the letter however I do recall it being controversial at the time.

In a letter addressed to you, dated 2 January 1985, Dr Bloom states, "*in the past my committee has always been under pressure from patients and from the Society to seek increased funding for the purchase of commercial Factor VIII*" [DHSC0001260]. To the best of your knowledge, what did Dr Bloom mean by his committee being "under pressure" from the Haemophilia Society? How (if at all) did the Haemophilia Society influence the decisions and actions of healthcare professionals in relation to the purchase and use of commercial Factor VIII? If this changed over time, please detail when and why.

133. I am uncertain what Dr Bloom meant by his committee being "*under pressure*" from The Society at this time. However, reading the document, suggests that we must have had a regional day in Cardiff. By 1985, Professor Bloom had already lost at least one patient, if not more, to HIV. I can only assume, that he was "*under pressure*" to make sure that patients could be treated at all, because without American product at this stage there would have been little or no treatment available because of the systemic failure of successive governments to fulfil the David Owen pledge of self-sufficiency. At that point in

time, the only reason we had been pressuring doctors to get the extra funding necessary for heat treated product, for commercial Factor VIII from the United States, was that people could be treated at all. The UK was not self-sufficient at that time and the alternative was no treatment at all. We were seeking funding for more expensive, safer products that had been heat treated.

Please consider the letter from Dr Peter Jones to you dated 14 October 1986 asking for an "*official view*" from the Society about the collection of data about HIV status and AIDS without individual informed consent, and the memo you wrote dated 17 October 1986 about this issue [HSOC0015334]. Did the Society formulate an "*official view*" and if so, what was it and how and to whom was it communicated?

134. I can recall the incident, however, I cannot recall the outcome from it, documentation should be available from The Society files.

By letter dated 31 August 2005, you wrote a testimonial for Dr Peter Jones. In the letter, you state that "*From my personal experience of sitting in on his consultations, great care was always taken to communicate the risks and the benefits of therapies to patients*" [WITN3365014_001, page 124]. Please explain when you sat in on consultations, why you did so and what you observed. Did you sit in on consultations with any other doctors? If so, please set out who else you sat in with, when and why. Please set out what you observed in relation to each doctor.

135. I believe that this was in relation to my induction, and I may have sat in with other physicians, as stated above at paragraph 80. Again, this is a very long time ago and I have no independent recall until prompted by this question. If I attended any patient meetings, I was always there with the patient's consent.

Section 5: Relationship with the Government

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

136. This was a main feature of my work from 1983 onwards, and my meetings with civil servants were frequent and we spoke about self-sufficiency, progress towards self-sufficiency and the need for compensation. At those meetings I was generally unaccompanied by a member of the Board. If, however, I was meeting with ministers and I remember in particular meetings with Sir John Moore, Kenneth Clarke and Edwina Currie, I was always accompanied, usually by the Chairman.

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

137. At civil service level, Roger Moore was my main contact. In relation to how those relationships were formed, the key people had generally contacted The Society and we kept the relationship going on a regular basis. The Society would regularly write to civil servants and would try to follow up thereafter with meetings. We would always encourage members to write to their local MPs. The Society did not have a local MP as such. Therefore, MPs would only be able to be contacted by members of their constituency. The work of members lobbying their MPs would go on in the background and if we were coming up to a time when a campaign was about to be launched, I would, for instance, let a civil servant know that we were about to embark on that course of action, which would inevitably result in a meeting with a minister. In the meantime, however, the media was on the go, the Sunday Times in particular was carrying authoritative information from The Society.

138. Meetings with the Government were not regularly scheduled however, it was on a needs basis that we used to meet. Our offices were very close, because

for much of the time The Society was based in Trinity Street, SE1 very near to The Department of Health at Elephant and Castle.

At page 92 of your evidence to the Penrose Inquiry [PRSE0006087], you stated that you always wrote to Government ministers in advance of your meeting with them to set out the points that you wished to discuss and following the meeting, you wrote confirming your discussion. Please provide all such letters to the Inquiry.

139. Unfortunately I no longer hold any of these documents, they were left at The Society when I was made redundant.

Please provide a detailed account of your meetings with Government ministers and/or civil servants and/or other representatives of the Government. In particular please set out the following:

a. How often did such meetings take place?

b. Who did you meet with?

c. Were the meetings minuted, and if so by whom?

d. What were the purposes of the meetings?

e. What was discussed at the meetings?

140. As stated in response to the preceding question I no longer have access to my documents from my time at The Society. I know that I kept a distinct file for Department of Health communications. However, since leaving The Society I have clearly had no control over those documents. As stated above, these meetings took place on a needs basis. Who we met with would depend on the issue in hand. For example, we sometimes met with the Secretary of State or a Health Minister, Ken Clarke, Sir John Moore, or Edwina Currie. At civil service level, I would often meet with Roger Moore. To the best of my knowledge, we did not minute the meetings as such. We would write a note of the meeting afterwards. Again, the purpose of the meetings would depend on

what was needed at that time. It might be self-sufficiency, it might be compensation.

5.1 The Supply of Imported Blood Products

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.

141. From recollection this would have been decided by the Executive Committee following advice from the Blood Products Sub-Committee.

When and why did the Haemophilia Society begin to lobby the Government against a prospective ban on the use of imported blood products? How did lobbying against a prospective ban on imported blood products relate to the Haemophilia Society's goals and objectives, as you understood them? [Please consider the following documents when addressing these questions: PRSE0003827; HCDO0000394_094].

142. I cannot recall specifically when this lobbying would have commenced, however, it was thought at the time, that the need and benefit of the treatment would far outweigh the risks. Of course, this was also based on the advice and guidance that we were receiving from the Medical Advisory Panel and the Department of Health. These were not the kinds of decisions that would be made unilaterally by the Executive Committee. Such discussions would be held by the Executive Committee and a decision then made whether or not to seek the advice of the Medical Advisory Panel. That was always the route as I recall it. I was not necessarily always the person who went to the Medical Advisory Panel because we had a Blood Product Sub-Committee and the Chairman, Ken Milne, would be the person who would conduct those liaisons with the Medical Advisory Panel. Having listened to some of the evidence provided to the Inquiry, in particular the presentation on Professor Arthur

Bloom, I have to say, I have been quite surprised by some of the evidence. I have been struck by how unrealistic some of the approaches to the entire situation were. At the level of Professor Bloom, I had assumed, and I think I was entitled to assume at the time, that they would be looking in greater depth at what information was available. On reflection, it appears that some of the truth was being withheld from us, and in turn in was being withheld from patients. Listening to the evidence, albeit with 20/20 hindsight vision, I would have expected infinitely better of all those involved in providing the advice.

At page 5 of the 1983 Annual Report of the Haemophilia Society, it was reported that, "*Lord Glenarthur... was asked to ensure that blood products would continue to be imported until Britain was self-sufficient in blood products. The Minister reassured us of this...*"[HSOC0019506, page 5]. Did the Haemophilia Society receive further 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 department that made them.

143. The advice to continue using imported blood products was reiterated many times by the Medical Advisory Panel and the Department of Health. From memory, it would be normal practice that the Government would have those conversations with Centre Directors and the Centre Directors would have correspondence with the Government in return. The members of the Medical Advisory Panel were in turn Centre Directors and they would pass that information down the chain to The Society. It is most likely, that we would also have similar conversations with the Government at our regular meetings. However, I have no independent recall of any specific instances.

144. Our meetings with the Government, were, in my recollection, very open and candid.

5.2 Self-Sufficiency

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

145. From recollection, such decisions would have been made by the Executive Committee with the assistance of the Blood Products Sub-Committee. The position on self-sufficiency had been in place from the early 70's, long preceding my employment.

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.

146. I believe that this would have been communicated even before Dr David Owen made his commitment for self-sufficiency, because that came about very much as a result as pressure from The Haemophilia Society, and of course in those days there was reference to this Non-A Non-B Hepatitis, in fact, I do not know whether they were even calling it Non-A Non-B in those early days. There was continual lobbying of the Government towards self-sufficiency from the mid-1970s onwards by The Society. In the early days, it would have been down to people like John Prothero, Ken Polton, Ken Milne and Alan Tanner to handle the lobbying, that would have been before my time.

147. The Society had no effective administrative back-up to support them in that lobbying. There was no great campaign other than the occasional newspaper article and suchlike, because life was not that sophisticated in those days. We most certainly did not have the benefit of iPads, laptops and emails. I do not recall The Society's position changing over time during my tenure.

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 those assurances?**
c. **Did the Haemophilia Society rely on those 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?**

148. Dr David Owen gave that assurance in no uncertain terms. During the early days of my involvement in The Society, as referred to above, we received a sudden invitation to go and meet Dr Gerrard Vaughan, Minister for Health. We were given a very warm welcome, and he reassured us that he knew exactly the door that we had come to push upon but not to push too hard, because he was very happy to confirm that money was now going to be invested into BPL in order to achieve self-sufficiency. That was a complete turnaround by any Government since Dr David Owen left his post as Secretary of State for Health. After Dr David Owen had left his post the Government had essentially gone back on what had been pledged. I think people stopped just short of saying "*no, we're not going to go for self-sufficiency*". It simply dropped way down the priority list, and hepatitis and HIV were the major part of the cost of that. There was also a core group of MPs we were always feeding information to. We could not afford to feed it to every MP in the House, however our membership also made a lot of contact with their MPs with prompting and encouragement by The Society to do so.

5.3 Reduction of Risk of Blood Products

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

149. From recollection this would have been the Executive Committee, the Blood Products Sub-Committee and the Medical Advisory Panel.

What were the key issues that the Society pursued?

150. We continually pressed for self-sufficiency but I have no detailed recall of other issues.

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.

151. The risk was evident from the 1970s, hence pressure on Dr David Owen which later led to an assurance broken by successive administrations. The flagship demand was always for self-sufficiency. However, realism came into it with the advent of HIV and AIDS, which meant that we were led to believe that the best thing to do was to continue treating with imported product. Whilst it appears that evidence may have been less supportive over time, the advice did not change. The conversations continued with the Government and the civil servants.

Were any assurances given by the Government in response to the communication of the Society's positions? If so, please set out what those assurances were, who gave the assurances and when they were provided.

152. I believe that there must have been some assurances given by the Government in response to The Society's position. The annual report of 1983, already referred to above, included such information from Lord Glenarthur.

In a press release dated 20 December 1984, the Society stated that they had drawn the attention of officials to their concern about donor screening in the United Kingdom some months previously [DHSC0000684]. Please set out who did this, which officials were contacted, when and how they were contacted.

Please describe what response you received if any. If you have copies of any letters or meeting notes recording this concern, please provide them.

153. I recognise the document referred to within this question, unfortunately, I have little other recollection of it. I do not hold any other documents that would be of relevance to this question.

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?

154. The press release referred to in the preceding question refers to the urgency of moving on with heat-treated products. That did not change during my tenure, and I have no access to any further documents.

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.

155. I do not know who else The Society could rely on for assurances other than the Government or individuals in public office. Whilst it relied on the advice of the Medical Advisory Panel, they were equally relying on information coming out of the Government. The passing of time does not enable me to identify individuals but such information could be available from Haemophilia Society records.

5.4 Campaign for Compensation

When did the Haemophilia Society begin campaigning for compensation?

156. I cannot recall the specific date that The Society began campaigning for compensation. The minutes of the Executive Committee should reflect this. However, I do recall that The Society was receiving many requests for financial assistance, and The Society could not afford to sustain them. I recall writing to the Department of Health suggesting that it at least consider a hardship fund in the meantime. I believe that that is what initially led to the first tranche of Macfarlane Trust money. The Government set out its stall quite early in stating that it would not provide any compensation because that would appear to be an admission of negligence and the Government did not admit that there had been negligence. There were individuals who sought compensation and as such The Society put them in touch with lawyers around the country who could take up the fight for such cases. However, even that was not a payment of compensation that people received, because there was no admission of liability.

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

157. The whole reason for establishing this campaign was the enormous financial burden being placed on individuals and families through having this terrible long term illness. Haemofact 15 [WITN3429023/BAYP0000010_144] set out how The Society was going to begin the campaign in earnest and set out how the campaign would operate. Initially it was believed that those infected would have died very quickly; in fact this was not to be the case. However, the longer that it went on the greater the hardship became for those individuals and The Society was inundated and simply could not afford to keep up with the financial demands being placed upon us by our membership. The Society, therefore, had to think of an alternative way to fund and assist these individuals.

Please identify who was responsible for determining the Society's position in relation to campaigning for compensation.

158. The Executive Committee was responsible for determining The Society's position in relation to campaigning.

What were the goals and priorities of the campaign for compensation?

- **a. How were the goals set?**
- **b. To what extent (if any) 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?**

159. At the time, The Society was fighting for whatever it could get out of the Government that failed to recognise its involvement in the crisis. They certainly were not prepared to admit liability so that was the first hurdle that had to be overcome. We had to take the moral high ground and use that as pressure to exert upon the Government. However, we were still a very small organisation. I do not believe that The Society had a goal as such at that time.

160. I do not believe that there was a figure in mind, because whatever figure you had in mind they would only give you half of it, at least. I believe the goals of The Society were recorded at some stage. To some extent The Society achieved its goals, by receiving the £10,000,000 initially to set up the Macfarlane Trust. The legal cases then commenced and that pressure was also continuing, albeit The Society was not part of those cases. The litigation

was part of a distinct legal process, and our advice is always to follow the lawyers in the litigation. I did not really see the Macfarlane Trust as compensation, it was more of a hardship fund.

161. The goals of The Society were communicated to the Government, as the whole campaign was directed at the Government. The Government avoided any statements and assurances in relation to compensation, because they would not admit liability.

Considering your response to question 93, to what extent (if any) was the campaign for compensation informed by the views of the Society's membership? Did these differ from the views of the Haemophilia Society Executive Committee, as you understood them?

162. I cannot recall any diversions of views at that time. At that stage, we were just trying to get anything for our members. It would, therefore, be difficult to be divergent until you had an end product.

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?**

163. I believe that the call for compensation for people with haemophilia who were infected with Hepatitis were starting at the time of my departure from The

Society. From recollection, the Executive Committee had to be very careful that it did not portray people with haemophilia as people were always asking for more. As a result, the Executive Committee, may not have pursued this with the enthusiasm that it should have in hindsight – the greatest informer of all time. There was always a fine balance to be struck between preserving the good name of people with haemophilia and ensuring that they received the support they required from Government. I cannot recall any specific assurances made by the Government to The Society in relation to compensation during my period at The Society.

Section 6: Litigation

What role did the Society play in the HIV litigation? [You may find it helpful to consider RFLT0000004].

a. **In the newsletter dated October 1988, members of the Haemophilia Society were advised "*Please feel free to check your situation with the society – and it is easier to deal with those enquiries when they are in writing...*" Why did the Society invite these enquiries? Who dealt with the enquiries from members? What were members told when they made such enquiries? Where did the information that was provided to them originate from?**

b. **Please include consideration of the information under the heading "compensation" in [HCDO0000276_033].**

   i. **Why was this document prepared? Who wrote it? When did they write it? Who was it provided to?**

   ii. **The document states that "...*we have to say that, on present known facts and upon our judgment of the advice we have received, the prospect of the majority of claims succeeding is remote*". How was this "judgement" made? By whom was it formulated and when? What was the basis for this judgement? 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.

164. As I recall it, The Society's role in the HIV litigation was minimal. We provided a list of potential solicitors to those members who wanted to follow such action. We attempted to identify solicitors spread around the country. In relation to the second document I have been referred to, this is part of the annual report. This information would have been provided to the membership. The annual report would obviously have been written collectively by the Executive Committee. The annual report repeated substantial sections of Counsel's opinion. A Counsel could be considered as an external expert that was used to write the content of this document. Unfortunately, I have no further independent recall after 34 years.

165. On 24 October 1990, I sent an urgent letter to all Society members [WITN3429024/RFLT0000004]. The letter said "*You will no doubt have seen, read or heard at least something of the speculation which is being conducted in the media about the possibility of an out of court settlement. It is being implied that negotiations are taking place between lawyers representing both sides - ie YOUR lawyers and the Government lawyers – to establish an acceptable out of court settlement. The Haemophilia Society is not – and cannot be – involved in those negotiations. If they are taking place they are being held between the lawyers and any level of settlement will be determined by them and the court. It is therefore important that you get in touch with your lawyer in that connection.*"

On 16 February 1987, you sent counsel's opinion on the prospects of success of the litigation to members of the Medical Advisory Panel [HSOC0023188]. Why did you send this to the Panel? Was this action agreed by the Executive Committee of the Society?

166. This action would undoubtedly have been agreed by the Executive Committee. I suspect, that this was shared with the Medical Advisory Panel for information. As organisations we had the commonality of purpose to do our best for people with haemophilia.

By fax dated 27 September 1989, you informed lawyers for claimants that a doctor had contacted you with "vital information" for the litigation [HSOC0023179]. Who was this doctor? What information did they have that was relevant to the litigation?

167. Unfortunately, I have no idea at this juncture. I would suggest the person to speak to would be Tony Mallen.

In a letter dated 4 January 1991, you wrote to a solicitors' firm and stated that the Society had, "*worked consistently to guide people towards accepting what we feel certain counsel will regard as a fair and reasonable settlement*" [HSOC0015341]. Please explain what "*work*" had been undertaken by the Society to "*guide*" people towards accepting a settlement. How did the Society come to this view? What advice had the Society received and from whom? What did the Society consider to be a "*fair and reasonable settlement*"?

168. Throughout the entire litigation we had been at pains to show people that their relationship in relation to this was with their solicitors, and not with The Haemophilia Society (as referred to above). We were without function in relation to the litigation, as such, when people were offered settlement that had been negotiated by their lawyers, they were told that they should follow the advice of lawyers, and we could not become involved in that. On recollection, the work that had been undertaken by The Society to guide people towards accepting the settlement was simply to obtain the correct legal advice. The Society could not hold a view as to whether a settlement was fair and reasonable. It was up to individuals to hold that view.

In the Bulletin in February 1991, it was noted that the Society's campaign for compensation had come to an end at the end of 1990 because the Government has acknowledged the need for an out-of-court settlement. The article said "*The offer carried the condition that the great majority of those affected must accept the offer, or it would lapse*" [HCDO0000279_009]. It goes on to say that the campaign "*must be hailed as a success*".

a. **What was the Society's position in relation to the adequacy of the settlement?**

b. **What did the Society advise its members about accepting the offer or not?**

c. **The article states that although the campaign had ended, "*the problem has not disappeared, and the tragedy is not forgotten*". What was meant by this? What was anticipated that the Society would do going forwards?**

169. As stated above, The Society could not hold a view on the adequacy of the settlement. This was to be contained within correspondence between the solicitors and their clients. The Society played no role in advising its members in relation to accepting the offer or not. I have no specific recall in relation to "*the problem has not disappeared, and the tragedy is not forgotten*". However, this could mean that the illnesses, suffering and needs were ongoing.

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 your report to the Haemophilia Centre Directors' Annual Meeting 1993, dated 29 September 1993, under the heading Hepatitis, where you refer 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] you have written that "1993 has been a difficult year for the Society". Why had 1993 been a difficult year? Please limit your response to matters relevant to the Terms of Reference.

170. The document referred to within this question was drafted by myself on 28 September 1983 as stated on the document. I believe that this would have been sent to all of those infected with Hepatitis C and had enquired about the Hepatitis C litigation. It provided them with the names of two experienced lawyers who knew the background and were prepared to take on the cases. As always, correspondence would have been approved by the Executive Committee and advice given to them from the lawyers and any sub-committee that had been established. I believe, at this stage there was a lawyers' steering group. I believe the subcommittee consisted of Tony Mallen, Graham Ross, and Mark Mildred. I believe that this sub-committee would have been established towards the end of the '80s when the HIV litigations commenced.

171. 1993 had been a difficult year for The Society as referred to within the document where I refer to issues with staffing and office accommodation. The Society had been through a very difficult period up until this point. I cannot recall any specifics at this stage, however, as certain things calmed down, it gave people more

opportunity to focus on other areas, such as staffing, which resulted in difficult times. There were also Board Members who felt that enough time and resource had been spent and devoted to HIV and Hepatitis C and that the time had come for a change of priority.

Please consider your General Secretary's Report dated 10 May 1990 [HSOC0024261, page 2] where it is noted that there had been discussions about suggesting to the Government that there should be an inquiry "*on the same basis [as Thalidomide]*". It goes on to state your view that you hoped that there would not be an inquiry. Please describe the meetings that are referred to in this Report and explain when, with whom and why you met, as well as the content of those meetings.

172. Given the passage of time, I have no independent recall of this, but it is clear that we decided that the political route was the most expedient to achieve our goal. Whilst I cannot recall any further specific detail over and above that contained within this report, I do recall feeling that I did not want people to have to wait for many years for the outcome of an inquiry before things changed. The need for assistance for people with haemophilia and HIV was immediate and urgent; they should not have had to wait for the outcome of an inquiry.

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.

173. The events relating to this public inquiry all happened after my time at The Society. Whilst some initial discussions took place, as referred to above, I do not

recall any particular actions during my time at The Society to pursue a public inquiry.

Section 7: Interaction with Trusts and Schemes

At a Meeting of the Trustees of the Macfarlane Trust held on the 12 April 1988 [MACF0000002_003], you are noted as present. Please confirm your role at this Macfarlane Trust meeting and any other(s) you attended. If you were a trustee, please explain how you came to be appointed and for what period you were in that role?

174. I never held the position of Trustee of the Macfarlane Trust, or any other position. Whilst I was involved in the initial set up as a consequence of The Society receiving the original cheque to establish the Macfarlane Trust, I was never an office holder. Whilst I accept that I attended some meetings of the Macfarlane Trust, I did what I could to attend as few as possible, given that I had no specific role. If I attended, it was always through my role at The Society, when the Trust was in the process of being established.

175. Given that I had no role at the Macfarlane Trust, I can only presume that I was in attendance at this meeting as somebody who was involved in haemophilia care and knew of the needs of the community. I attended some initial meetings of the Macfarlane Trust given the involvement of The Society in its initial set up and the administration of grants in the early days before it was officially established.

In the 1988 Annual report [HCDO0000276_021] it is stated that during the first eight months of 1988, the administration of the Macfarlane Trust was carried out by the Society. Please explain why this was the case and what the Society did during that period.

176. This is correct. The cheque for £10m was originally passed to me to receive on behalf of The Society. The Macfarlane Trust, or any trust for that matter, did not

exist at the time. The accompanying press release from the Department of Health stated that the money would be spent for the benefit of people with haemophilia and HIV with immediate effect. However, given that there was no trust established The Society had to do what it could in the short term. There was nobody to administer any payments and people needed the money as soon as possible.

177. It was decided that The Society would provide some of these grants on trust until such time as the Macfarlane Trust was formally established. Luckily the Macfarlane Trust agreed to repay these sums to The Society when it was eventually formally established. There was some resistance from some MFT trustees to this course of action when it was eventually established.

178. Decisions in respect of payments to be made to individuals were made by the Case Committee (referred to above). Applications would be received and considered by the Case Committee and then a decision made by the Society Trustees as to whether the payment should be made or not based on the recommendations of the Case Committee. I believe that the document [WITN3429025/MACF0000002_003] states that The Society used £25,671 of its own funds during this period.

In a document headed "Some random and preliminary thoughts" dated 28 January 1988, you wrote that "*...when one opens a honey pot one expects flies!!*", *you described those in debt as "classic mismanagement by mismanagers!";* that "*members do not understand the difference between items campaigned for and those for which one has to settle*". and that there was a "potential problem" that beneficiaries would "*plot and scheme to take advantage of the Trust*" [HSCO0013404]. You also set out different options for how the Macfarlane Trust was established and whether it should be a charitable trust. Please explain:

a. **What did you mean by the sections and matters quoted above?**
b. **Who was this document prepared for? To whom was it disseminated?**

c. Did you obtain expert assistance to provide the Society's view of whether the Macfarlane Trust should be established as a charitable trust? If so, please explain who provided that advice and what it was. If not, on what basis did you feel able to set out the different options?

179. I do not recall drafting this document. However, it appears to be a confidential document I drafted for the benefit of the Board. I recall at the establishment of the Macfarlane Trust a number of individuals had technically spent the money before it was received, as many people do if they believe that they will be getting a sum of money when they have nothing.

180. We certainly obtained expert assistance when deciding how the Macfarlane Trust should be established. I also visited a number of other disaster funds and explored how they were established and how they administered their funds. It appears from a footnote in WITN3429026/HSOC0013404 that I refer to an accompanying letter from Painsers & Co in respect of the options available.

Once the Macfarlane Trust was established, what role did the Haemophilia Society play in the operations of the Macfarlane Trust? What role did the Society play in making grants, or in making decisions about grants, on behalf of the Macfarlane Trust?

181. Other than providing Society nominated trustees, as did the Department of Health, as far as I am aware The Society did not play any role in making grants or decisions about grants on behalf of the Macfarlane Trust. The Society's Annual Report of 1988 [WITN3429027/HCDO0000276_021] refers to the establishment of the Macfarlane Trust. It states "*Late in 1987 the government gave £10 million to meet the special needs of people with haemophilia and HIV infection. Early in 1988, in order to administer this charitable fund, the Macfarlane Trust was created as a separate legal entity. This is particularly important in safeguarding the confidentiality of its work. However, during the first eight months of 1988 the*

administration of the Macfarlane Trust was carried out by the Society. We continue to appoint six of the ten Trustees. Now that the Macfarlane Trust has established its own identity, with its own premises and staff, the two organisations enjoy a co-operative working relationship".

182. This is supported by the Macfarlane Trust Newsletter of June 1989 [WITN3429028/MACF0000004_107] where it states "*The Trust is now totally independent of the Society, although of course our Chairman and some Trustees are involved with both. We do of course work in close co-operation with the Society, but this is in parallel rather than with much overlap, and we do not share confidential personal information without your permission".*

It is understood that initially there was no allocations policy in place. On what basis were the grants made by the Haemophilia Society during this time? To what extent did your document noted in question 106 play a part in the allocations?

183. Allocations were initially made on the basis of the Haemophilia Society's welfare grant payments, I believe. I have no recollection of there being a written protocol in relation to this. It was simply based on need.

In a letter dated 2 February 1988, you referred to a survey of patients with HIV, ARC or AIDS which was "*vital to help us with the allocation of the grant of £10 million*" [HSOC0004761]. Please explain to whom the survey was circulated, what the results of the survey were and how this informed the allocation of monies.

184. My recollection is that this would have been the initial registration information which would have been sent to all Haemophilia Society members – we had no record of who had and who did not have HIV. The survey was returnable to the

Macfarlane Trust in a pre-paid addressed envelope. This was a vital step which gave people the opportunity to register with the Trust.

Were any problems encountered in your performing a role with both the Haemophilia Society and Macfarlane Trust? If so, how were they resolved?

185. My role was purely formative in the initial set up of the Macfarlane Trust. I had no direct relationship with the Macfarlane Trust thereafter, only in my capacity as General Secretary of The Society.

At a meeting of the Macfarlane Trust held on 22 August 1988, a proposal by the Allocations Committee for the new Allocations Policy was discussed [MACF0000002_007].

a. **Were you a member of the Allocations Committee? If so, how were you appointed?**
b. **As a feature of the Allocations Policy, it is noted that Single Payment Grants, "*will be available on the basis of need in its broadest sense, and not on the basis of income*," and they are not just for, "*helping to overcome a problem by paying a bill...but by providing things which offset stress*".**

   i. During your period of involvement with the Macfarlane Trust, did these remain the guiding principles for allocations?

   ii. Were you aware of the subsequent introduction of an Income & Expenditure form [see for example MACF0000041_056] for grant applicants to complete? If so, please explain why it was introduced. In your view, was the requirement to complete it in keeping with the initial Allocations Policy presented at the above meeting?
c. **To the extent that you have not already answered this above, please provide details of your involvement in determining applications for financial assistance and support at the Macfarlane Trust.**

d. Why were you involved in drafting a section 64 application for the Macfarlane Trust? What was your involvement?

186. I certainly was not a member of any committee of the Macfarlane Trust. I note that I was in attendance at this meeting, however, I have no recollection of this meeting. In relation to the section 64 grant, that was clearly something formative that I had been involved with in the early stages of the establishment of the Macfarlane Trust; unfortunately, my recollections are not clear. I anticipate that was the only reason that I was present at this meeting. I was not involved in any of the allocations of the MFT. I think it would be fair to say that my relationship and the relationship of The Haemophilia Society as a whole with the Macfarlane Trust at this stage was uneasy. On the whole, it was not a totally happy, cooperative working relationship. They were an organisation in their own right, as we were.

187. As stated above, I had no involvement in the allocation of funds at the Macfarlane Trust post the establishment of the Trust, and as such I cannot comment on points b or c of this question.

At the same meeting as mentioned at paragraph 111, the attendees discussed the possibility of members of the Trust attending Regional Centres to meet medical and social workers and trust members to answer queries and put a face on the Trust [MAFC0000002_007, page 8]. How many such meetings took place? Where were they held? What was said and done at the meetings? [MACF0000004_107]

188. As stated above, I had no involvement in the Macfarlane Trust and as such, can provide no further information in relation to these meetings.

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 Haemophilia Society. It was discussed 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 the Macfarlane Trust and what those concerns were?

189. As stated above, the relationship was never an easy one. From the content of this document it can be seen that we were hoping to improve channels of communication between The Society and the Macfarlane Trust, in addition, the members of The Society were struggling in obtaining what they felt were sufficient grants from the Macfarlane Trust.

In the minutes from the Haemophilia Society meeting of the Policy Committee held on 15 April 1992 [HSOC0017235], you 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 and schemes during your time at the Haemophilia Society.**
c. **What did you mean by better relationship and communication?**

190. As previously stated, the relationship between The Haemophilia Society and the Macfarlane Trust was not always an easy one. All other trusts and schemes were established after my departure from The Haemophilia Society. As a result of these trusts and schemes being established after I left the Society, I had no contact with them. I cannot recall specifically what I meant by "*a better relationship and communication*", however, there is always scope for

improvement in such relationships. As stated elsewhere in this statement, The Haemophilia Society had the right to nominate Trustees to the Macfarlane Trust.

In the minutes of the meeting of the UK Haemophilia Centre Directors held on 10 January 1993 [HCDO0000015_007], the issue of the Macfarlane Trust not offering funding for artificial insemination and ovulation test kits is mentioned.

a. What were the views among the members of the Haemophilia Society about the lack of funding offered for fertility treatments up until this point by the trusts and schemes?

b. It is noted in the minutes of the meeting of the Macfarlane Trust dated 9 May 1988 [MACF0000002_004, page 3], that you raised the question of making grants to enable artificial insemination where young husbands had AIDS, and that this issue was deferred for more detailed consideration on a future occasion. Do you recall if there was more detailed consideration, and why the principle was not adopted by the Macfarlane Trust?

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 and when?

191. Given the passage of time, I have no recall of the views held at the time. In relation to parts b and c of this question, I believe that this meeting was again part of the formative stages of the Macfarlane Trust, before they had their own offices. I cannot recall whether The Society had any input into particular procedures that would be covered by funding from the Macfarlane Trust.

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

192. From my recollection, the Department of Health had the right to nominate trustees for the Macfarlane Trust, as did The Society. However, as stated above, I was not involved in the day to day running of the Macfarlane Trust after it was formally established.

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

193. My recall suggests that no amount of money could ever be adequate to meet the needs of a group so severely afflicted by this tragedy. Individual's lives had been completely turned upside down and it affected not only them but also everybody around them. It also affected people differently resulting in differing needs.

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

194. I cannot recall raising any specific issues with the Department of Health in relation to the Macfarlane Trust.

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

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

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

195. As stated above, the Alliance House Organisations did not exist during my tenure at The Society. After I left The Society, I commenced work with the Primary Immunodeficiency Association. I recall, that trustees would sometimes come to see me to complain about The Society or the Macfarlane Trust, however, these were just general moans and groans in relation to the work of both.

Section 8: Relationship with Pharmaceutical Companies

8.1 Financial Relationships

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.

196. Financial contributions were invaluable to The Society in meeting its income objectives. There was an even-handed application process made to each of those companies and to a huge number of charitable trusts. Every year applications would be made to these organisations and an equal opportunity was provided to all to respond as they felt fit, there were certainly no benefits deriving from it. Any funding received would be acknowledged within publications. As a charity we were under an obligation to do everything we could to fund the work and not refuse any donations. We were also required, as a charity, to publish the names of those who supported the work.

197. As stated in the letter provided by Thompsons to the Penrose Inquiry, dated 9 November 2011 [WITN3429029/PRSE0003528] The Society's approach to funding changed considerably during the 1980s and, as The Society employed

more staff, its ability to raise more funds increased, which resulted in the pharmaceutical companies also increasing their donations. The letter also explains that "*any donation made would have no influence over the conduct of the Society, its attitudes or its communications with its membership. The pharmaceutical companies who were prepared to donate sums to the Society were prepared to do so not in return for promotion of their products*" [WITN3429029/PRSE0003528, page 2].

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

198. BPL was a governmental organisation and as such could not provide financial support until much later, when that status changed. However, that made no difference to the relationship The Society had with the company. There was a huge degree of mutual respect between the two organisations. Given its structure, its relationship with The Society was slightly different to corporate pharmaceutical companies.

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

199. At this distance of time, I have very little recall. I cannot recall any substantial research funds held by The Society and the distribution, if they existed, would have been a matter for the Executive Committee. From recollection, I believe there was a Research Grant sub-committee, at some stage, which would consider applications in their own merit. I do not recall any monies being provided

to the BPL during my tenure. Compared with what was happening at BPL at the time, the funds held by The Society would have been peanuts.

200. In relation to benefit derived from the relationship with BPL, I believe the only benefit would have been the free exchange of information and knowledge of the likely contribution to the need for Factor VIII in the United Kingdom.

201. There were absolutely no funds provided to any of the pharmaceutical companies for research, or otherwise, during my tenure as far as I recall.

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.

202. When I joined The Society, there were already relationships in place with some of the pharmaceutical companies. Whenever it came to funding a specific event, publication or activity for The Society, we would simply send a round robin to all of the main pharmaceutical companies seeking their support. There would be various informal meetings to discuss the state of the market. This would occur, for example, if a company was going to have a supply problem, they would let physicians and sometimes The Society know of that problem. This would assist us, so that we were not suddenly inundated with queries from anxious members without the background to the fact that they were being switched from one product to another, for example.

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?

203. On the whole, the contributions from pharmaceutical companies remained pretty constant throughout my tenure. However, the needs of The Society grew hugely on account of HIV and that was reflected in the fact that we got enhanced funding from the Government. It also resulted in us making further applications to pharmaceutical companies, and other charitable trusts and owners. The advent of computer technology assisted this aspect of our work.

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?

204. I have no detailed recall at all of the different relationships at this stage. However, there were large and small companies and their donations usually matched their ability to pay.

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?

205. I think their motivation was purely that of keeping The Haemophilia Society, a patient organisation, that did not have a huge number of members anyway, in existence to assist in contributing to its work. As far as I recall, there was never an expectation that The Society would provide anything in return.

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

206. As far as I recall, this was not a requirement of the pharmaceutical company, rather it was a requirement of charity law and transparency.

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.

207. As far as I recall, The Haemophilia Society, through its activities and functions, did not attempt to assist pharmaceutical companies to promote their products or public image at all.

In the General Secretary's report in November 1989, you state that, "*Armour are very much about the business of improving their public image in the UK prior to obtaining a full product licence for MONOCLATE. I have spent more than a little time with them discussing issues – and extracting money – However, this is time consuming and reminds me one of the 'there's no such thing as a free lunch' maxim!*" [HSOC0024307, page 1]. Please comment on this statement. What did you mean by "*there's no such thing as a free lunch*"?

208. This was a confidential document prepared for the Executive Committee. On reflection, given the passage of time, I cannot recall specifically what I meant when I said "*there's no such thing as a free lunch*". However, I suspect that I simply meant that I would be invited to lunch and suddenly find myself involved

in a lengthy discussion, which was very time-consuming, as I have said elsewhere within the report.

In the General Secretary's Report dated November 1989, you stated that you, "*understand that [Armour] are willing to grant £10,000 for publication costs; that they are keen to meet travel costs to lobby the US Congress; that they are looking into funding the 1990 Executive conference; and so on*" [HSOC0024307, page 1]. Why did Armour Pharmaceutical Companies offer to fund these activities? Was the offer accepted?

209. As stated in response to a previous question, all the pharmaceutical companies would have been approached to fund some of these events. Armour simply responded to that and expressed an interest in funding those activities. I have no recall as to whether they actually funded any of those events or not at this stage.

In the General Secretary's Report in November 1989, you also stated that the Medical Advisory Panel, "*included within its agenda a presentation of Monoclate by Armour Pharmaceuticals*" [HSOC0024307, page 2]. Why was this included in the agenda? Who asked the Armour representatives to attend the Medical Advisory Panel meeting? Why? Was this the same presentation referred to in [HSOC0010954]? If it was not, please explain what the latter presentation was. Please set out each and every occasion on which pharmaceutical representatives attended meetings of the Medical Advisory Panel, the topic that was discussed, who invited them and why such an invitation was issued.

210. I have no recollection as to why this would have been included on the agenda, or who would have asked Armour representatives to attend the Medical Advisory Panel meeting, I suspect, that it would have been Ken Milne who was Chair of the Blood Products Sub-Committee at the time. I believe that this was the same

presentation as referred to in WITN3429030/HSOC0010954, however I cannot be certain.

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

211. As stated in response to earlier questions, it would have been the Editor of Publications who would have requested this article. I cannot really comment on Alpha's expectations from the publication of this article.

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.

212. As far as I recall, The Society did not publish or disseminate any articles or publications in exchange for, or with the expectation of receiving, financial contributions. If a publication had been sponsored by a specific pharmaceutical company, then that would have been commented on within the publication.

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.

213. The Society would not publish or disseminate any articles or publications in exchange for, or with the expectation of, receiving financial contributions or other benefits from pharmaceutical companies.

8.2 Other relationships

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

214. The Haemophilia Society did not rely on pharmaceutical companies for assistance or support other than financial contributions. As a charity, The Society could not rely on anybody for anything. As a charity, if they budgeted on that basis and the money did not come in, they would immediately be in financial difficulty.

What relationship did the Executive Committee-members of the Haemophilia Society have with pharmaceutical companies?

a. **The Executive Committee minutes dated 9 December 1980 mention that John Prothero met the Managing Director of Travenol [HSOC0019919_022]. If you are aware of the purpose of this meeting, please explain what it was.**

b. **NOT RELEVANT**

c. **Did any other representatives of pharmaceutical companies join the Haemophilia Society, either while they still worked for the pharmaceutical company or after they left?**

215. I have no knowledge of the meeting which took place between John Prothero and the Managing Director of Travenol as this took place before my appointment.

216. NOT RELEVANT

217. Membership of The Haemophilia Society was open to everyone without restriction. Therefore, I am unable to comment as to whether any other representatives of pharmaceutical companies became members of The Society during my tenure.

What was the purpose of the Blood Products Sub-Committee meeting with pharmaceutical company representatives? Mention of a meeting is made in Executive Committee minutes dated 14 March 1985 [HSOC0029476_045, page 2].

218. Having read the minutes, I believe that the purpose of the meeting was to discuss items of common interest. For example, supply, availability, safety of blood products and recent developments.

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.]

219. From my recollection, The Society did not rely on any communications from pharmaceutical companies for assurances or opinions on the safety of blood products. However, The Society would, of course, be influenced by the decision of the now MHRA to grant licenses to products for use in the United Kingdom.

What was the purpose of pharmaceutical representatives speaking at Regional Group meetings of the Haemophilia Society?

220. I have no recollection of pharmaceutical representatives speaking at Regional Group meetings of the Haemophilia Society. I recall them attending various meetings, but do not recall any lectures or presentations being conducted by them.

In Haemofact, Release No.2, the Haemophilia Society informed its members that, "*we have been keeping close contact with the pharmaceutical companies involved in the importation of concentrates from America. Their improved methods of blood collection have been noted*" [PRSE0000088]. Please elaborate on this statement. Which pharmaceutical companies were the Haemophilia Society keeping close contact with during this period? Who were the main points of contact? What were the improved methods of blood collection that were noted?

221. Unfortunately, my recall does not extend to 37 years ago. It is a fairly detailed question that I am being asked. My vague recollection, and it is only a vague recollection, is that they were stopping seeking donations from high-risk donors of plasma.

In the Haemophilia Society Annual Report in 1985, you noted that, "*the Society also kept in close contact with the pharmaceutical companies which supplied the UK with Factor VIII to meet the shortfall between our needs and NHS production. The companies were able to import large amounts of heat-treated Factor VIII at short notice after the decision was made to use only heat treated material*" [HSOC0019504, page 7]. Which pharmaceutical companies were the Haemophilia Society keeping close contact with during the period? Who were the main points of contact? What was the purpose of these communications?

222. The purpose was to secure a safe supply of heat treated product. The companies would have included Armour and Travenol but from this distance, I cannot recall the actual companies, or their contacts. The two names I do recall were, Barry Barber from Travenol and later Alpha, and Chris Bishop from Armour.

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 [HSOC0019594]. 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?

223. I have no recall of who wrote this article, but the Editor of Publications would have been responsible for its publication. The Editor of Publications was always a member of the Board. As previously stated, if there was an article published by a member of the Medical Advisory Panel, or a clinician, we would not ask another clinician to peer review that article before it was published. The Society was a charity and we did not have that luxury.

In a memo from you to Ken Milne dated 5 February 1988 [HSOC0015356] you referred to "the current round of consultations with the Companies". What "round of consultations" were you referring to and what, if any, involvement did the Society have in the consultations? Please explain also why you were "totally unconvinced" by BPL's assertions about the safety of their dry-heated product and what you meant by there being "big moves afoot there". You may be assisted by also considering [HSOC0015355].

224. Given the passage of time, I have no recollection as to the consultations that I referred to within this memo. Quite often, when I attended such meetings, it was simply to take a minute. I would sometimes interject to remind the Board of previous discussions however decisions were ultimately made by the Board.

225. I have no recollection as to why I was "totally unconvinced" by BPL's assertions about the safety of their dry-heated products given the passage of time.

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.

226. Unfortunately, given the passage of time, I have no recall in relation to this letter from Graham Barker to Norman Pettet.

Section 9: Other Issues

To the best of your knowledge, at any point, did Haemophilia Society staff and committee-members purposefully or unintentionally destroy documents relevant to the Terms of Reference of the Infected Blood Inquiry?

227. I left The Society in 1994, decades before this public Inquiry was announced. I am convinced that absolutely no records pertaining to haemophilia and HIV were destroyed during my tenure – in fact, I had a passion to retain all documentation in relation to this medical tragedy as I saw there would be a future benefit to society at large. I have a vague recollection of receiving a telephone call after my departure, where I was informed that documents were being destroyed. Given that this happened after my departure, I cannot say whether any of these documents related to matters relevant to the Inquiry's Terms of Reference.

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 the current List of Issues.

228. As stated elsewhere in this statement, in participating in the BBC Panorama programme, I was asked to consider a letter received by Professor Bloom from somebody within governmental health bodies, that was heavily redacted. The content of this letter, however, stated, something along the lines of that "*at no cost should patients be taken off the existing products because there was a disaster about to happen*". I have never had a hard copy of this document, but believe it is of vital importance to the Inquiry.

229. I also feel that it is again important to emphasise that The Society was a very small, vulnerable organisation. We did not have the luxury of having articles peer reviewed. We did not have the luxury of spending vast amounts of time contemplating documents, because we were besieged with telephone calls, enquiries and everything else from people who were in a deep state of shock about the news they were being given about their health and about their futures. In addition, we were attempting to continue to provide support to those with haemophilia who were fortunate not to be involved in the contaminated blood scandal.

230. Whilst the Society did what it could to publish documentation, and information for its members, at all stages we reminded members to discuss their individual treatment plans with their Centre clinicians.

231. The Inquiry has taken a number of clinicians to the first Haemofact in May 1983. This was the letter drafted by Professor Bloom, in response to the article in the Mail on Sunday on 1 May 1983. I have no recollection of any clinician disagreeing with the advice provided by Professor Bloom at that time. Professor Bloom was considered to be a leader in his field, but there were others, however, nobody

else volunteered any contrary views to those provided by Professor Bloom at the time.

232. As far as I recall, none of the board members and trustees were medically qualified. Their qualifications in relation to haemophilia, were from the fact that they had lived with the condition or were supporting a family member who was living with the condition, as can be seen from my Exhibit [WITN3429006]. Undoubtedly, some of the trustees would have discussed their personal treatment plans or those of their family members, with each other, however these discussions never took place in the boardroom. These individuals were actually going through these events themselves as matters were unfolding with a fortitude you could not imagine. They looked at each other like brother and sister sharing all of this trauma as it was developing. It should not be forgotten, that the Haemophilia Society was formed of individuals who were themselves struggling to live with haemophilia. Those individuals were themselves taking, receiving and acting on the same advice.

233. It was very difficult for me as an individual, without haemophilia, to work so closely with these individuals who would ring me to say "*I've got my results, and it is not good*". It was an extremely difficult time for all involved. It was a very demanding job and I used to be at my desk very often soon after seven in the morning, until seven at night. It was almost constant, the telephone to the ear, listening to the most heart-breaking stories. I was helped through my time at the Haemophilia Society by my faith. However, there were times when even I would question things. I recall receiving a telephone call from an Essex clergyman saying that everybody with HIV was damned.

234. It could also be very lonely. When I joined The Society, there were only two of us working in the small office just off Trinity Street. There were times in the early days when things were really bad. Another thing that helped me through, were others who worked for similar charities at the same time. I developed lifelong

friendships with some of the individuals I met during my time at the Haemophilia Society.

235. From watching the Inquiry proceedings, I have seen that a number of witnesses have been asked about subscription to the Lancet and the British Medical Journal ("the BMJ"). The Society did often receive the Lancet and the BMJ, but for the reasons explained elsewhere in this witness statement we did not have the time to read them. Neither did we have the medical background to fully understand the content. It was for that reason that we would rely on our Medical Advisory Panel. When we rarely had the opportunity to skim through these papers, a skim is all that it would be, if any articles that we thought were of importance would jump out at us, they would be photocopied and disseminated to the Executive Committee.

236. Despite the small size of The Society, we were internationally recognised. I would also do what I could to remain in contact with other societies around the globe. I had particularly strong links with United States, Canada, and Australia. We were there to rely on each other. We would attempt to share information where we felt it would be relevant to another country as well. However, again, it would all come down to time. It was extremely busy and we did not always have the time to consider international elements in detail.

237. At a time when the scientific world was confronted with a new virus, and there were so many unknowns, The Society had little option but to rely on the members of its Medical Advisory Panel. A number of the members of the Medical Advisory Panel were also members of the UKHCDO. Therefore, they were not only discussing issues at Medical Advisory Panel conferences or meetings, they were also discussing things in the context of the UKHCDO. In the event that members of the Medical Advisory Panel became aware of a development, I anticipate that they would discuss those matters amongst themselves outside the Medical

Advisory Panel meetings. However, I cannot be certain. That was just the sense I got.

238. My view of the UKHCDO however, was that it was very secretive. It published its annual statistics, which we always received, but of course they were virtually always incomplete because Geoff Savidge (St Thomas's Haemophilia Centre) would not contribute towards them. It was therefore always very difficult to rely on any statistics from the UKHCDO as we were aware that they were incomplete and lacked information from one of the biggest Centres in the UK. I believe that the UKHCDO could have worked more closely with The Haemophilia Society. Possibly, the fact that we had to have our own Medical Advisory Panel speaks to the fact that the relationship between The Society and the UKHCDO was not perfect and we needed this additional support.

239. There was a strong relationship between The Society and Professor Bloom, Peter Jones, Elizabeth Mayne, Mark Winter, Ted Tuddenham, Peter Kernoff, Brian Colvin and Christopher Ludlam. There were a number of longstanding members of the board of The Haemophilia Society, for example, Reverend Tanner, and Ken Polton. They would have forged a number of these relationships in the early days.

240. I have often reflected on the events that happened over 30 years ago, and it is very easy to stand back and think, "*oh, you got that one wrong*!". Maybe we did, but we could only act on the information that we were being provided with at the time. Whilst we were aware that some clinicians had put all of their patients onto heat-treated factor quite early on, the advice that we were receiving overall from the Medical Advisory Panel was that this was not necessary. I have no recollection of any of the members of the Medical Advisory Panel raising concerns with the advice that The Society was providing. It must also be remembered, that there would not have been enough heat-treated product to

support all patients. My overriding thoughts, as I reflect on those matters, relate to:

a. the concern and puzzlement that successive British governments failed to fulfil the Dr David Owen promise of self-sufficiency.
b. the extraordinary plight, anxiety and suffering of all those caught up in this greatest medical tragedy of all time and my heart goes out to all those concerned. Many of them had become good friends.

Statement of Truth

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

Signed: GRO-C

Dated: 18th January 2021