Witness Name: Karin Pappenheim
Statement No: WITN4504001
Exhibits: WITN4504002 -
WITN4504008
Dated: 14.05.2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KARIN PAPPENHEIM

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 November 2020.

I, Karin Pappenheim, will say as follows: -

Section 1: Introduction

Question 1: please set out your name, address, DOB and professional qualifications

1. My name is Karin Pappenheim of GRO-C, London GRO-C I was born on GRO-C 1954.

2. My professional qualifications are set out in my CV attached at **WITN4504002.**

Question 2: please set out your employment history

3. I was the CEO of the Haemophilia Society from 30 March 1998 to April 2004.
   I would describe myself by profession as an experienced CEO with over 20 years experience of leading and managing national voluntary sector organisations, mostly health-related. My employment history is set out in my CV [**WITN4504002**].

Question 3: 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.

4. As CEO, I was a member of the Association of Chief Executives of National Voluntary Organisations (ACEVO). See https://www.acevo.org.uk. From ACEVO's current website,

the purpose is stated as 'Together with our network we inspire and support civil society leaders by providing connections, advocacy and skills. Our members include the leaders of small, community based groups, ambitious medium-sized organisations, and well known, well-loved national and international not-for-profits.'

5. My membership of ACEVO was an important source of learning and development for me as CEO of the Society, and ensured I kept up to date in my professional practice. ACEVO is the professional membership body for voluntary sector chief executives. I, as an ordinary member, held no formal role in the organisation. As an ordinary member, I had access to professional development in the form of educational meetings, peer support (e.g. action learning sets) and examples of good practice which I could use in my own work. For instance, on joining the Society, I referred to the ACEVO Model Service Agreement between voluntary organisations and chief executives. This provided a template on which to base my contract of employment with the Society.

6. I was also a trustee of the National Council for Voluntary Organisations ('NCVO') 1999 to 2005 and of Terence Higgins Trust ('THT') 1998 to 2003. These were voluntary unpaid roles. Those roles enabled me to develop my experience and professional practice as a CEO: they provided me with the opportunity to be a trustee board member. As a CEO, working with the board of my own charity, the Haemophilia Society, it was important for me to acquire the complementary experience of being a board member. Acting as a board member for THT, I was also able to deepen my knowledge about HIV, and hence my understanding of how this affected the lives of our Haemophilia Society members who were co-infected with HIV and HCV. I learned that there was a historic relationship between the two charities dating back into the earliest days of the appearance of the HIV virus in this country.

Section 2: Previous Evidence

Question 4: Please confirm whether you have provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. If you have, please provide details of your involvement and copies of any statements that you made.

7. I have not provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus and/or

hepatitis B virus and/or hepatitis C virus infections and/or Creutzfeldt-Jakob disease in blood and/or blood products.

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

Question 5: 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.

8. When I joined the Society in 1998 as CEO, it was a registered charity (number 288260) and company limited by guarantee in England and Wales. Its mission was stated as *'Caring for people with haemophilia and other bleeding disorders'* [**WITN4504003**]. The remit of the charity was UK wide as well as international. Please refer to the Memorandum and Articles of Association [**WITN4504004**].

9. I have cited the 1998 issue of the Bulletin, [**WITN4504003**] as it was the first one produced after I was appointed, and it introduces me as new CEO. This issue shows the range of services provided (page 12) for members, the scope of campaigning activities at the time relating to HCV and HIV, and the emerging issues around new variant CJD. As a national voluntary organisation, in common with other such bodies, the Society combined advocacy and campaigning with provision of support services for individuals and families. The charitable objectives of the Society did not change during my tenure, however the balance of resources allocated to advocacy, campaigns and provision of support services varied, depending on resources available and strategic decisions taken by the Board as to how to prioritise. This is typical of any such charitable organisations.

10. The core purpose of the charity remains unchanged today, I believe. Noting the points made below with regard to governance improvements, these did not change the core purpose of the charity, which is stated in the legal governing documents. The governing body of the charity was and is the Trustee Board, which holds responsibility for strategic decisions about priorities and use of resources. When I joined in 1998, board discussions had already begun about the possibility of some change to the constitution, and how it might be improved. Questions being discussed were about the election process, term of office and whether trustees might be appointed from outside the haemophilia community. The latter point related to a widely discussed governance matter (then and now) relating to diversity of skills and experience on trustee boards: it was increasingly common practice for charities to seek a diverse mix amongst their trustees and the Society was therefore following good practice in considering this. This was one of the changes implemented in due course to the constitution (see my answer below) in 1999 enabling the appointment

of a trustee with relevant skills/experience from outside the haemophilia community. George Levy, a charity CEO in the medical field, was appointed as the first such 'independent trustee' in due course following that change made through a vote taken at the AGM.

11. Another key development – which was very significant during my tenure – was the greater focus on other related bleeding disorders, notably von Willebrands. This increased the number of potential beneficiaries of the charity's work, as there are a far larger number of people affected by VWD disorder, and this widened the scope to women. The launch of the Women's project was very important, therefore, during my tenure, as the charity was recognising and seeking to engage with women affected by VWD whose needs had not been addressed previously.

12. During my tenure, another significant development was the decision to recruit a staff member in Scotland. Minutes of the Trustee Board meeting 25 March 1999 [**HSOC0029689_025**] how the start of the Board's devolution strategy, and a working party was set up to consider the matter. As CEO, I was a member of the group, together with representatives from Scotland, Wales and Northern Ireland. In due course, this led to change with regard to Scotland.

13. The charity was registered separately in Scotland. This was in response to Scottish devolution politically, and a recognition of the devolved powers of the Scottish Parliament and the different situation in Scotland for our members. This change was also a response to the views expressed by Scottish members who perceived the organisation as too London-centric and who wished to have a stronger sense of identity for the Haemophilia Society in Scotland. As mentioned later in my evidence, during my tenure, a Scottish base was set up and a worker appointed. This development is also very relevant with regard to the campaigning and advocacy work, which is discussed later in my evidence. There were opportunities for the Society to pursue its advocacy campaigns directly with the Scottish Parliament and MSPs, which were not available in the same way in Westminster Parliament. The Scottish groups of the Society were very active in the campaign. This is discussed later in my evidence. In my final report to the board [**HSOC0020091_012**] an overview of the Scottish project and evaluation report is included. In summary, the aim of the Scottish charity was to address the needs of people with bleeding disorders in Scotland. More detail can be found in the report itself.

14. I have been able to review the Memorandum and Articles of the charity, which were in place during my tenure, and those current now. The Board and members made changes to the Mem and Arts when I was with the Society in 1999 [**WITN4504004**]. I refer to those in more detail in response to question 6 below.

15. Finally, during my tenure, the Society undertook a re-branding, as part of a strategy to increase the charity's profile and enhance marketing, fundraising and campaigning/advocacy.

Question 6: Please describe how the organisation was structured, including the governance arrangements and the day-to-day management and running of the Society. If this changed over the period of your tenure, please set out those changes.

16. The Society was a national charity, with an elected board. The legal governance of the charity was then, as it is now, a Trustee Board, which delegated operational responsibility to a CEO. I believe the Inquiry will be able to confirm this by reference to the Articles and to statutory report and accounts 1998 to 2004, which I do not have, and minutes for the members over this time period The staff team reported to me as CEO, and the membership. Within the staff team, each had specific roles and job descriptions within: membership services; finance; administration; and fundraising. Specialist staff roles included a Hepatitis C and an HIV officer, as well as a children and families officer, and a benefits advisor.

17. The trustee board met regularly, at least every two months; extraordinary meetings were sometimes held where specific urgent issues needed to be resolved. Within the Trustee Board, there were a number of Honorary Officer roles: Chairman, Treasurer and two Vice Chairmen. The charity also had an honorary President (Lord Alf Morris from 1999) and a number of Vice Presidents. The membership elected the Board and the Chairman, and trustees were then appointed the Honorary Officers from within their group. There was a Royal Patron: HRH The Duchess of Kent. When I first joined, the Chairman was Chris Hodgson who was later succeeded by Roddy Morrison who took office following the AGM on Saturday 5 July 2003.

18. During my tenure, I was responsible for a number of governance reviews, and modifications were made to the Memorandum and Articles on 24 April 1999. This can be seen in **WITN4504004.** On joining, as new CEO it was part of my role to review the charity's governance, and advise the board on improvements. These are the Articles under which the charity operated during my term of office. The changes were to improve

governance. Those improvements were in a sense administrative, relating to terms of office, for instance, and (with regard to the appointment of an independent trustee already mentioned) to bring more diversity of skills/experience onto the board of trustees. Within the governance framework, the Trustee Board and CEO take the strategic decisions about priorities and use of the charity's resources. The Society's lawyers at the time were Paisners, later Farrars, and Anne Marie Piper was the senior advisor who was involved in this work.

19. The structure of the charity included local membership groups of the Society, which provided a focus for membership peer support, fundraising and campaigning. I believe there were approx. 25 groups across the UK during my tenure.

20. The local groups (called branches) operated within a framework established by the Society and a group bank account scheme. This is a specific and recognised charity structure with local branches forming part of the national charity. As branches of the charity, the groups were active in fundraising and providing peer support to members in their own locality. They also took part in campaigns with the Society. The groups were not separate legal entities, they formed part of the membership structure of the Society and hence under charity accounting practice the national charity accounted for the group finances. Each group had to follow the accounting and other rules set by the national charity, which involved submitting regular reports and accounts. Groups held regular meetings, providing peer support for individuals and families, and reported their activities to the Society. News and information from the groups was included in the Bulletin (the Society's member magazine) and all groups with contact details were listed in the publication. A board member was assigned to each group to act as a liaison point between the branch and the national charity. These board/group links were appointed by the trustee board from amongst their members each year to the best of my recollection.

21. A number of special interest groups were also active as part of the organisation during my time with the Society: the Manor House Group for those affected by HepC and the Birchgrove Group for those affected by HIV/HCV. Those groups were also not separate legal entities, to the best of my recall. As special interest groups I would say their role was primarily to represent the interests of those who were infected with HCV or HIV/HCV, and to provide peer support. Both had interests in campaigning and advocacy in support of their members' interests. As part of their roles, the Society's specialist workers for HCV and HIV maintained communications links with the two groups. They did not operate in the

same way as the local group branches. The Society provided funding to each of the two groups to support their work; details of which can be found in Board minutes of the time.

22. Relationships between those special interest groups and between each and the Society changed over time. Sometimes there would have been tensions and disagreements, although the Society worked hard to maintain communication with those groups and to be inclusive. There was a great deal of anger amongst members of both Manor House and Birchgrove because of the impact of infected blood; the co-infected HIV/HCV group had lost many members who had died. Bereavement and loss in such a small community was strongly felt, and very painful. A sense of injustice about the lack of accountability and responsibility by Government for the infection fuelled the anger, together with dissatisfaction with such financial assistance offered and the inequity of providing a scheme for those who were HIV co-infected and nothing similar to those infected with HCV. Such issues generated internal conflict, and disagreement.

23. Relations between the Birchgrove and Manor House two groups were strained when I joined in 1998 and there was a proposal discussed on my advice as CEO about arranging a formal mediation process. This was not agreed, and I am unsure whether any specific reasons were given by either Birchgrove or Manor House about why they refused mediation. I would say that relationships continued to be difficult to maintain during my tenure, and this was challenging to manage. In the end, it was not possible to continue. The Manor House Group eventually separated from the Society and continued as a separate group outside the charity. Some years later the Birchgrove Group also separated.

24. I do not recall any other changes during my tenure.

Question 7: Please describe the relationship between the Board of Trustees, Council, and the day-to-day management of the Society.

25. As referenced above in my responses to questions 5 and 6, the legal governance structure of the charity, consisted of the Trustee Board, which appoints the CEO, to whom day to day management of the organisation is delegated. As CEO, I reported to each Trustee Board meeting on operational matters. The Board also delegated responsibilities in three key areas to formal Sub Committees: Health, Resources and Information and Communications. Each was chaired by a Trustee Board member, and I was a member of all three as CEO. The Society holds in its archives copies of the minutes for all Board and Sub Committee meetings held during my tenure, and I have been able to review copies provided in preparing my evidence. The minutes provide a detailed record of strategic and operational matters discussed, and of decisions taken.

26. The Council had no governance role, and had no delegated powers; its role, to my recollection, was to provide a forum for representatives of the Society's local groups and the Trustee Board to meet twice a year. There was no formal relationship that I can recall; the Council was part of the way the Society engaged with its local groups (branches) and functioned mainly as a forum for meeting together, twice a year. The Council did not undertake any programmes of work or activities in its own right. Further information on this can be found in member communications by the Society during my tenure, and in Board minutes.

Question 8: Please explain what your responsibilities were, who you reported to, and how your role changed over time (if at all).

27. I was recruited in 1998 to lead and manage the charity as CEO on a permanent full time contract. On 30 March 1998 I joined the Society as an experienced CEO and senior manager of charities, with a professional background in communications, advocacy and public affairs, and in leading campaigns and advocacy. I understood that my experience in advocacy was an important factor when the Trustees decided to appoint me, in light of the active campaigns relating to infected blood the Society was pursuing at the time. I do not have a medical background or qualifications, but my career has been mainly in the health sector as senior manager/CEO of health related charities. I was recruited through an open selection process, involving written application and panel interviews. The previous CEO Tony Wilson had left some months previously. There are Trustee Board minutes of the period prior to March 1998, which reference the Board decision to recruit a new CEO and which the Society holds. I do not hold copies of those documents. The Society's chairman Chris Hodgson and Treasurer Nick Lawson, acting on behalf of the Board, led the recruitment. Please see my full CV for career history: **WITN4504002**.

28. The responsibilities were as would be expected of a charity CEO, a combination of operational (resource and staff management), strategic and governance. An indication of the types of responsibilities and the immediate priorities for my first six months in post can be seen in the 'CEO priorities July to December 1998 document' [**WITN4504005**] agreed with Trustees in my first year. This included strategic planning, fundraising/finance, and public affairs, leading the campaign for recombinant and on HCV, communications, membership services, health policy and organisational/internal (such as setting priorities for staff, introducing staff job descriptions and contracts and a process for pay reviews). As CEO my responsibility was to deliver the goals and priorities set by the Trustees. For

further detail, refer to the Board minutes 1998 to 2004 and archive copies of my reports to the Board during this time, which the Society should hold.

29. My role as CEO was full time, and it was a very full agenda and a demanding workload, involving much out of hours work and a great deal of travel across the UK and internationally, given the wide remit of the charity and spread of our membership.

    As CEO, I was accountable to the Trustee Board. My priorities were agreed annually as part of the business planning process. I was appointed by the Board as an experienced CEO. My line manager was the Chairman of the Board, and I reported directly to the Chairman the full Board on work carried out to achieve the priorities agreed and to agree future priorities. My reports were in written form. Evidence of this can be seen in the minutes of the Trustee Board meetings during my term of office and refer to my operational reports, which were provided to the board meetings. I do not hold copies of all Trustee Board minutes, but have been able to obtain these from the Haemophilia Society archives to assist in preparing my evidence. For additional detail it would be necessary to review all the Board minutes during my time in post. I do not hold copies of annual business plans. Annual business plans and minutes of the trustee board meetings over my time in post should be held by the Society.

30. As CEO, I was responsible for management of the staff team (ten staff each with specialist roles and responsibilities). All staff were responsible to me as there was a flat structure. Staff roles and personnel would have changed over the time I was in post, but no major restructure or change took place. For evidence of the staff structure and the individuals in post during my tenure, the Bulletin is a good reference as post holders of the time are mentioned in the publication and some issues actually list the whole staff team. Due to funding constraints, towards the end of tenure, I recall that some redundancies took place.

31. As CEO I had responsibility for managing day-to-day operations of the Society, including staff, and all HR processes, and finances within delegated authorities derived from the budget and operational plans agreed annually with trustees. My responsibility as CEO was to deliver the goals and priorities agreed by the Board. It was part of my role to advise the Board on operational matters, and to make recommendations on which the Trustees would be able to make informed strategic decisions, such as deciding the focus of the campaigns. When I joined in 1998, there was a wide range of issues, which the Board needed me to review and advise on. These are set out in the July to December 1998 priorities document mentioned above: **WITN4504005**.

32. As an employee, I did not act in the capacity of a director. The trustees and board hold responsibility legally as company directors acting within charity and company law and within the Society's governing documents. My responsibility as CEO was to advise the board on good governance, to ensure the charity was compliant and adhered to best practice. I acted as Company Secretary from January 1999 for a period of time (the exact dates would need to be checked against Haemophilia Society files, as I do no hold this information). This involved responsibility for ensuring statutory report and accounts were prepared and submitted to the Charity Commission and regulators.

33. During my tenure as CEO, the board and I were advised by Paisners, later Farrar and Co, the charity's appointed legal advisors. Anne Marie Piper was the solicitor who provided that advice, an expert in charity law, during my term of office. Minutes of some of the AGM and board meetings over 1998 to 2004 document her attendance and advice given in her capacity as legal advisor to the charity.

34. As CEO I conducted a governance review (referred to as a 'constitutional review'. 1999-2000. Changes were made to the charity's governing documents in 1999, as referenced above.

Question 9: What methods (if any) did you use to report the Haemophilia Society's activities to the Executive Committee and/or Board of Trustees?

35. Each year I prepared operational plans and budgets for approval by the trustee board. Copies may exist in the Society's files. A record of the decisions and of priorities agreed can be found in the trustee board minutes over my term of office. My reports were in written form to the board of trustees.

36. As CEO, I undertook a number of strategic reviews reporting to the board. These included constitutional; governance; devolution and campaigns. The reports would include options for consideration by the board, and further evidence of this can be found in the board minutes.

Question 10. Please list all the different committees and advisory bodies that you recall were set up within the Society that provided medical advice and/or scientific opinion relevant to the Inquiry's Terms of Reference to the Haemophilia Society. Please describe the purpose, functions and responsibilities of each committee or advisory body.

37. During my tenure, reporting to the board of trustees, there were three sub committees: resources, health and information/communications. A board member chaired each. See evidence document [**HSOC0024114**]. This is my joint report with Dr David Evans, to the Trustee Board 18 June 1998 which describes the sub-committee roles. For further evidence it would be necessary to obtain archive copies of minutes of the sub committees from the Haemophilia Society, as I do not hold these documents.

38. Regarding the question about which committees provided medical advice and/or scientific opinion, the Health Sub Committee was the formal sub committee of the board with a remit covering blood products; HIV and HCV; other infections; and both information and policy issues, health policy, as it might affect the interests of people with haemophilia. It met twice a year. The sub committee's role was advisory to the board. The role was to consider the latest information and research in relation to haemophilia treatments, health services, infections and to formulate policy recommendations to the Board. The sub committee also kept a watching brief on developments in health policy, such as changes in the NHS. It functioned as an information forum ensuring the Society was up to date with current knowledge and practice in relation to haemophilia and other bleeding disorders. Members of this committee included individuals with medical knowledge. During my tenure at least two or three members were doctors, and a further two or three nurses. As mentioned above, the chair was a board member. As an example of the scope of this committee's work, I cite two sets of meeting minutes: 3 August 2000 [**WITN4504006**] and 10 September 2003 [**WITN4504007**]. I believe these documents give a good indication of the range of topics discussed.

39. For further information, refer to the minutes of the Health sub committee meetings 1998-2004. I do not hold my own copies of those documents which are within the Society's archives and copies have been made available for me to review in preparing my evidence.

40. Later in my evidence, I discuss the role of the Medical Advisory Panel, which was complementary to the Health Sub Committee, but purely advisory (see [**HSOC0029689_045**] Trustee board meeting minutes 21 June 2002 at which membership of the three sub committees was approved).

3.1 Interaction with Other Organisations

Question 11: Please describe the relationship between the Haemophilia Society and the UK Haemophilia Centre Directors Organisation ("UKHCDO"). What was your role and involvement with the UKHCDO?.

41. I have reviewed document **HSOC0024017**. **HSOC0024017** refers to the Trustee Board discussion 28 January 1999 and is a copy of my report to that board meeting on initiating regular meetings with UKHCDO.

42. During my term of office, as CEO I was involved in the Society's relationships with the World and European Societies of Haemophilia, the Macfarlane Trust, and individual national haemophilia societies. With regard to the World and European organisations, both were membership bodies and the Society was a member organisation. For a period of time, whilst I was CEO, the Society provided the Secretariat function for the European Society.

43. There was no *formal* relationship between the Society and the UKHCDO. However, there were regular meetings between the two organisations, which I would attend, often with a board member. This is evidenced in document **HSOC0024017**, which is a copy of my report to the board on 28 January 1999 about initiating regular meetings with UKHCDO. **HSOC0024017** shows the information sharing topics and areas for collaboration between the Society and the UKHCDO which were proposed.

44. My role as CEO was to represent the Society at meetings with UKHCDO, and this would be together with the Chairman and/or other board members. The purpose of meeting and collaboration was the advancement of treatment and care for people with bleeding disorders: the primary purpose of the charity. As a patient group, in pursuit of this purpose, collaboration with the specialist clinicians through their own membership body, the UKHCDO, was based on a sense of shared purpose to improve treatment and care.

45. If further detail about the meetings is required, the Inquiry would need to obtain minutes of the UKHCDO meetings and to cross-reference these to any agenda items at the Society's board or sub committee meetings. I do not hold such documents. From my recollection, there was a great deal of communication with the UKHCDO and collaboration on specific issues affecting the patient group. This would include provision of recombinant treatment, for instance, and improvements in NHS specialist care through the national care centres audit conducted by the UKHCDO, which latterly involved patient representatives. The UKHCDO held the national patient database, and this was very important in many aspects of patient safety during my tenure.

46. Over my tenure, the collaboration developed in response to the key issues each year. Further information on the patient database may have been provided already by witnesses

from UKHCDO. A further source of information on the relationship is the minutes of the Health Sub Committee 1998-2004. There were UKHCDO members on the sub committee and topics discussed at the Health Sub committee meetings show the health matters of concern to patients, clinicians and the Society. UKHCDO members are listed in the membership of the committee in the Society's records, they were appointed by powers given to the Board and membership was reviewed annually by the board of trustees.

47. As a specialised clinical area, the haemophilia doctors within the NHS are probably relatively small in number, and working in a highly specialist branch of medicine, which is funded and commissioned differently (or was during my time). As such, they had formed UKHCDO as a means of sharing clinical expertise and advancing standards of treatment and care, I believe, and it was in the mutual interests of the clinicians and the patient group to collaborate.

48. I would say that the role of UKHCDO members in the Society's work was to share their relevant clinical knowledge with our members (e.g. through writing articles) and to contribute their clinical knowledge as and when required by the Society's board (e.g. through the formal Health Sub Committee). The Society's member communications, especially the Bulletin (later titled HQ) during my tenure included regular reports on treatment issues, and on matters involving collaboration with the UKHCDO. To the best of my knowledge UKHCDO members were not ordinary members of the Society: this would need to be checked with the membership records of the Society. I do not recall whether the Society offered a special category of membership for professionals.

Question 12: Please describe the relationship between the Haemophilia Society and the National Haemophilia Alliance, including:

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

49. The Haemophilia Alliance was formed as a joint initiative between the Society and the UKHCDO in 1999 together with other Haemophilia-focused organisations, including haemophilia nurses and physiotherapists [**HSOC0024017**]. Inaugural co-chairs were Dr Mark Winter (UKHCDO) and Chris Hodgson (then Society chairman). Document **HSOC0024017**, the report to the trustee board 28/1/99 seeking views on the proposed Haemophilia Alliance, sets out the basis for the proposal for the Alliance.

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

50. The Alliance's aims were to establish a national service framework for haemophilia services and to abolish unacceptable variations in the quality of care for haemophilia patients. Stakeholder organisations to be involved included UKHDO and the Society representing clinicians and patients respectively, and other groups for nurses, physiotherapists and professionals involved in providing treatment and care. I do not recall any change in the original aims during my tenure.

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

51. Challenges faced by the Alliance were the inequalities in provision of care and of shortage of supply and funding for optimal care, recombinant treatment, and the need to persuade the Department of Health to address these issues. Further evidence would need to be obtained from records held by the Haemophilia Society and the UKHCDO.

52. My recollection is that the Alliance was a significant collaboration to address inequalities in care and establish a national standard of care, which could be audited. Those inequalities and variations were considerable. There were differences between Comprehensive Care Centres and local Haemophilia Centres; there were variations in the way patient care was provided. Haemophilia being a rare condition, requiring very specialist lifelong care, also relatively expensive to treat, it was a challenge (or 'obstacle' to use the Inquiry's word) to persuade NHS leadership and politicians to address these inequalities and to commit the resources required to ensure national standards of treatment and care for all.

53. When I joined the Society, recombinant treatment was clearly stated to be the treatment of choice for patients with haemophilia by the clinicians, and the patient group (see my later evidence on the recombinant campaign). The obstacle was to persuade politicians and the NHS to fund this as treatment of choice, which took some years to achieve. Other evidence of the so-called 'postcode lottery' in treatment and care provided to people with haemophilia exists in the form of research commissioned by the Society during my tenure, and published in member communications. The Health Sub Committee minutes are another source of evidence. As I hope I have made clear in this answer, there were significant obstacles faced by the Haemophilia Alliance in achieving its aims.

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

54. Progress was made to achieve the National Haemophilia Alliance aims. In terms of results, the audit of Haemophilia Treatment Centres by UKHCDO against the standards was a significant step forward, and during my time, a key development was the inclusion of patient representatives in the audit team. To the best of my recollection, this was progress in that including patients in the audit was a way of ensuring patients views/experiences were considered in auditing the quality of care provided. We did not achieve the over-arching aim of standardised treatment and care across the NHS; significant variations geographically and between centres still existed when I left. There was more work to do, therefore, to achieve standardised treatment and care, and work towards which would have continued into the future, and potentially still continues today.

Section 4: Knowledge of Risk

Question 13: When you first joined the Society:

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

55. When I joined the Society as a 'lay person', with no medical background, I had no knowledge of haemophilia or bleeding disorders generally, of the history of HIV and hepatitis infection, or of bleeding disorders. However, from my earlier career in sexual health, I had a reasonable knowledge of HIV, which was helpful. As a professional charity CEO, on taking up a new role, I would expect to rapidly familiarise myself with new subject matter, often complex and scientific. This was the case when I joined the Society. I was recruited for my experience as a CEO, and my background in advocacy and campaigns. On joining, I had to acquire knowledge as rapidly as possible in order to lead the campaigns. There was full information available within the Society e.g. various briefing documents and information resources provided for our members. I do not hold copies of any of the information, and have kept no documents relating to my employment with the Society, apart from those relating to my contract of employment. Any reference materials, which I had access to as CEO would remain in the Society's archives and records.

56. In terms of understanding the lived experiences of people with haemophilia and their families, including those affected by HCV and HIV, I was able to learn directly from the Society's members and from trustees who were living with these conditions. During my time, we employed specialist workers for HCV and HIV on the staff team, and I was able to look to their knowledge and experience as CEO. In addition we were able to draw on

the experience of our members affected by HCV and HIV through various consultations and task groups, as well as the special interest groups representing individuals living with these viruses. The Health Sub Committee, which I attended as CEO, was a key source of learning and knowledge for me in my role.

57. Over time, my knowledge deepened as there were other sources of learning, such as scientific research and the various stakeholder organisations in health. Those organisations included the UKHCDO, the Haemophilia Alliance, the European and World societies, the Long Term Medical Conditions Alliance and the Terence Higgins Trust. As CEO, it was part of my role to represent the Society and attend meetings with these and other relevant healthcare organisations. This also included the Department of Health. During the six years I was in post, through my involvement in those health care organisations, I acquired a deeper and broader knowledge and understanding of the complex field of haemophilia, and of current and past developments in health care, which affected the Society's members. At that time, I was literally immersed in the subject matter every day and would have acquired a deep knowledge – as a lay person not a scientist or clinician. Learning about the lives and experiences of people with haemophilia, and the impact of the contaminated blood disaster on this small patient group, was a huge part of my knowledge, acquired over six years of being part of the haemophilia community.

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

58. The risks of vCJD became a significant issue during my tenure. When I joined the Government had already recognised the 'theoretical risks' of vCJD infection through blood products and to make recombinant available for under 16s for this reason. New research and evidence of the risks was emerging, and of the ethical issues of testing when there was no cure. This evidence strengthened the Society's call for recombinant therapy for all haemophilia patients, as the safest treatment to avoid the risks of vCJD. Our role at the Society was to inform patients, and we were consulted by UKHCDO and Department of Health on how to communicate with the patient group, for instance, over product recalls. The Bulletin carried regular updates on treatment issues, and I can cite two issues in 2001 (spring and summer) [**HSOC0023040**; **HSOC0023041**] which carried information on vCJD in light of a plasma donor being found to be infected. This is discussed later in my evidence.

59. Again, this was an area in which scientific and medical knowledge was evolving during my time with the Society, and my knowledge had to keep pace. Sources of my knowledge about the topic included: the medical and scientific literature, the Department of Health, the UKHDO and our membership who were affected by the risks of vCJD.

(c) What did you know and understand about the risks of the transmission of other diseases from blood and blood products by others within the Society? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

60. As stated above, this was a fast moving, and changing medical and scientific field during my time, and my own knowledge had to keep pace. Our role at the Society was to keep patients informed, to advocate for the safest treatment and to engage in risk prevention initiatives, such as product recalls. As CEO, this required that I, with the board of trustees, had sufficient knowledge to fulfil the charity's mission and deliver those services to our members. Sources of knowledge included publications, attending conferences such as the European and World meetings, day to day contact with people with haemophilia and their families, with the clinicians treating them. All these were means of learning about this field. At that time, I was immersed daily in information and knowledge about this specialist area, and after six years had a very detailed understanding as a lay person. Having left this field 16 years ago, I have not retained that level of knowledge now.

Section 5: Communication and Dissemination of Information by the Society to its members

61. The factual answers to some of these questions may be found by referring to the Haemophilia Society's archives i.e. matters regarding the frequency of publications and the editorial process involved. Reference to the minutes of the Society's Information and Communications Sub Committee would be relevant for further evidence. I do not have access to these documents at the time of writing.

5.1 Publications

Question 14: Please detail the publications that the Haemophilia Society sent out to its membership during your tenure. 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.

Bulletin / HQ publication

62. During my tenure, the Society provided a quarterly Bulletin to its members. See reference to the first issues produced during my time, Issues 1 and 2, 1998 [documents **HSOC0019596; HSOC0023022**]. These were sent to all members. Over time, the key change was the move from print to electronic as the means of communicating, and at that time there was some reduction in the frequency of sending print copies partly to save costs. See my response to question 17 below. I was not directly involved in producing the publications, but I would be a contributor, writing my own articles from time to time. When I joined the Society, the editor of the Bulletin was Dr David Evans, and I believe that design and print were outsourced (i.e. not carried out in house by the Society's staff). I cannot recall the editorial production company and I note that this detail is not included in the publication.

63. In summer 2001, a new editor Carolyn Townsend took over and there was a competition amongst members to choose a new name. The Bulletin was renamed HQ (Haemophilia Quarterly) as a result. Dr David Evans continued as a contributor writing a section on Treatment updates. See Summer 2001 Issue 2 [**HSOC0023041**] and [**WITN4504003**; **WITN4504008**].

64. Initially the publications were sent out in hard copy to members by post. During my tenure the option to receive publications electronically was made available. I believe the online option was offered from 2001.

Other publications

65. Other publications included the following (all those listed below were either quarterly or two or three times a year) :

    a. HCV – fact pack of relevant information produced by the HCV worker and campaign briefings. Example: Campaign update: doc ref **HSOC0021235** 'HCV Campaign Update December 1998.
    b. C Change a quarterly newsletter for people affected by HCV and HIV produced by our two specialist workers on the staff team. Example: C change issue 16 September 2000, reference **HSOC0016621**
    c. HIV - relevant information produced by the HIV Worker
    d. Specific information was provided in the form of Factsheets, which were produced in response to identified needs to address members' concerns and queries. These factsheets were publicised in the Bulletin and on the website.

e. We also sent out on an ad hoc basis specific alerts (e.g. product recalls) and surveys.

Question 15: 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).

66. To the best of my recollection, the centre directors or Medical Advisory Panel ('MAP') members might have contributed articles but the editorial control rested with the Haemophilia Society as the publisher, and therefore ultimately with the Trustee Board. Hence, looking at issues of the Bulletin over 1998 to 2004, MAP and haemophilia centre directors can be seen to have contributed articles from time to time on topics of relevant interest to our membership. The decision as to what to include and publish would have rested with the Bulletin Editor. As CEO this was not my decision: as stated above I was not involved in the editorial process.

Question 16: 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).

67. The pharmaceutical companies had no direct involvement in selection of material for publication. As stated in response to question 15, the editorial control rested with the Society as the publisher and responsibility for selection of content sat with the Bulletin's editor. See also the guidelines and rules in place regarding commercial organisations: [**HSOC0012920**]. Those guidelines formed part of the charity's governance: they set out the independence of the charity and are a statement of the principle that whilst funding may be accepted, from commercial sources, this did not influence the independence of the charity. The guidelines and charity accounting standards meant that the Society acknowledged funding received towards publications by listing companies which had provided sponsorship, and we made it clear in our guidelines that such sponsorship gave the companies no editorial rights or influence. The choice as to what to publish was the Society's and responsibility was that of the Bulletin Editor. Further discussed under and referred to at question 15 above.

5.2 Other Communication to Members

Question 17: 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.

68. During my tenure, as well as distributing information through publications as set out in response to questions 14 to 16 above, the Society provided telephone information and advice services, which was a free phone 'helpline' offering advice on all aspects of living with haemophilia and related bleeding disorders, including treatment, benefits, travel and insurance. The Society also organised face-to-face meetings such as conferences and children and families events. The Bulletin (later known as HQ) listed those services for members to access. Services were coordinated and provided by specialist workers on the staff team (HCV, HIV, children and families, benefits) and volunteers involved with local and special interest groups.

69. Services were continuously developed and improved in response to the needs of members and through innovation, new ideas from our members, volunteers and staff. Fundraising by our professional fundraisers on the staff team helped to raise the funding to support services.

70. In my time we also provided Campaign and Marketing materials for members to use and fundraising materials. An example of campaign materials would be a template letter to use and marketing might be a fundraising pack. The charity's mission was to provide information, advice and support for people with haemophilia and bleeding disorders. In carrying out that mission we provided information, which was relevant and targeted to members needs, and interests (e.g. those living with HCV or HIV) and it was our aim to ensure that any information provided was timely, relevant and accurate. As digital technology developed, the website and electronic communications began to play a greater part in the dissemination of information between 1998 and 2004 alongside traditional print. From spring 2004, shortly before I left the Society, we started to offer a new email service for members and invited them to become e subscribers to a new HQ News electronic update. At that time, the website was also redesigned with the aims of fulfilling two requirements: a source of information and advice for members and a resource for members to interact with each other via forums.

Question 18: Did the Haemophilia Society receive direct inquiries from the public or members who required advice with regard to the safety of blood products? If so, how were these queries handled? Who would respond? What resources (if any) did the Haemophilia Society rely on to enable a response? Please set out specifically, to the best of your

knowledge, what advice and/or information the Society had and from whom that had been provided.

71. The Society did receive direct inquiries from members (to the best of my recollection and knowledge the general public would not have contacted the Society). We provided a Freephone telephone helpline for members (0800 018 6068 Monday to Friday 9am to 5pm. The specialist staff (HIV and HCV workers, information and advice workers) were responsible for responding to inquiries, which might come by phone or email. The resources provided by the Society were in the form of staff and any running costs for the helpline; this service would fall within the core purpose of the charity and hence was one to which the trustees allocated funding for direct costs. Staff provided a regular report on inquiries received, and this was reported to board, as I recall. This gave a breakdown of numbers of inquiries monthly, and topic of the query. I cannot provide more information due to time that has passed since my tenure.

Question 19: The Inquiry is concerned with infections of HBV, HCV, other causes of post-transfusion hepatitis, vCJD and any other diseases from blood products. For each of these diseases, what information and advice, during your tenure, did the Haemophilia Society provide to members regarding the:

72. During my time in post, the Bulletin (later HQ) was the primary communications method to inform all members of current and emerging issues relating to infections from blood and blood products. This is because this publication provided the overview of all relevant issues and concerns and was a useful way to sign post members to other sources of information (some being more specialist information provided by the Society, others being information from other organisations e.g. HIV charities). Specific information was provided in the form of Factsheets, which were produced in response to identified needs to address members' concerns and queries. These factsheets were publicised in the Bulletin and on the website.

73. I believe to the best of my recollection that the Society's members database (on Raiser's Edge at the time) enabled staff to record members interests in order to segment and target mailings (post or digital). This information about a member's interests would be obtained from that individual member (this would be a data protection matter in terms of the Society ensuring the accuracy of data held on the charity's system). Such use of member databases is common practice now and was evolving them: it is seem as a way to tailor the distribution of information to a member's preferences. This approach was starting during my tenure and might mean that, for instance, a member might be 'tagged' on the membership database as being interested in HIV, and this would enable the Society to

send relevant communications to those members only. We also sent out on an ad hoc basis specific alerts (e.g. product recalls) and surveys. I cannot give precise dates as to when such 'tailoring' might have been introduced. However, the standard would be to mail member information, I believe, to all members as this was one of the benefits of being a member of the Society.

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

74. I do not hold copies of specific publications; these would have been factsheets and fact packs. Factsheets were produced and regularly updated on HCV and HIV as previously stated. A fact pack would be a set of factsheets in a folder: I recall one containing HCV factsheets but there may have been others. Contents would have been updated when the information was out of date or no longer accurate. Hence, the change would have occurred in this way.

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

75. I do not hold copies of specific publications, these would have been factsheets and fact packs. Factsheets were produced and regularly updated on HCV and HIV as previously stated. Contents would have been updated when the information was out of date or no longer accurate. Hence, the change would have occurred in this way.

(c) Prevalence of infection amongst haemophiliacs? Please detail the method of communication and provide copies of publications, save for Bulletins, wherever possible. If this changed over time, please detail when and how:

76. I cannot recall a specific communication on the overall risks of infection, however, as stated above, the members magazine the Bulletin (then HQ) covered known and emerging risks as knowledge developed. As stated above, the Bulletin went to all members and that did not change; only the use of electronic as well as print changed. We regularly reported in our member communications, mainly the Bulletin, the numbers of individuals known to have contracted HIV and HCV, which would have changed over time as more accurate information became available. With regard to vCJD at the time, there was no test available and scientific understanding of this emerging infection was developing. I believe it was not possible to give a prevalence rate during my tenure.

Question 20: Considering your answer to question 19, what was the basis for the communications and advice provided by the Haemophilia Society to members about the risk of infection from blood products, health implications of infection and prevalence of infection amongst haemophiliacs for each of the abovementioned diseases? Specifically:

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

77. Medical professionals were involved in producing factsheets and their names were listed on the individual publications. The primary source for the Society would be the formal Health Sub Committee of the board. I do not recall involvement of the Medical Advisory Panel. Those selected to assist with specific topics were chosen because they were known to have expertise/specialism in that area. They might come from within the Health Sub Committee membership, but not exclusively, as there might be specific topics where that expertise/specialist knowledge was not within the membership of the committee.

(b) Who provided that advice?

78. This would depend on the specific topic, and the medical professional's area of expertise. The primary source for the Society would be the formal Health Sub Committee of the board. As stated above, in response to question 20(a), we looked to find the expert best suited to assist on a particular topic and area of specialism.

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

79. Depending on the topic, it was possible to identify medical professionals with expertise in that area. This might be identified, for instance, from scientific publications/research, which individuals had published, and through the knowledge of our specialist workers who would be familiar with experts in their field (e.g. HIV and HCV).

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

80. The Health Sub Committee was a source of information, through its members who were specialist doctors or nurses. At various times, the Society's board and staff might seek advice on specific topics and issues to inform decisions about the information to be sent to members. If the members of the committee did not have the relevant knowledge, it might be decided to ask the members of the MAP. On a day to day basis, I was not involved as CEO in responding to individual queries and cannot provide further detail on this.

(e) What was their advice in relation to each of the communications you have set out in answer to question 19 above?

81. I was not directly involved, as CEO, in producing each and every publication or communication to our members, as responsibility was delegated to specialist staff members (e.g. for Factsheets). I am therefore unable to advise what the medical advice was in relation to the communications set out in relation to question 19.

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

82. Where editing took place, to the best of my recollection, this would be to ensure that the communication was as accessible as possible to the 'layperson reader, and not to change the medical/scientific content. For example, this might have included improving wording for a non-specialist audience and avoiding scientific terminology, which might not be known by a layperson. Responsibility for editing the Bulletin lay with the editor, and for individual factsheets with the specialist worker concerned. As CEO, I was not personally involved in that work.

(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:

83. I am not aware that the Society received advice from other medical professionals, what that advice was (if it was received). I am not aware of a situation occurring, where advice from a medical professional conflicted with published advice and/or where that was not followed.

Section 6: Communication to and with Healthcare Professionals

Question 21: 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.

84. I cannot recall, but it is possible that there were times when we needed to communicate to healthcare professionals. This would need to be checked with the Society's archives. From memory, I cannot recall if there was any significant change over time.

85. Our primary focus as a charity was on the provision of information and support to our members, the patients and families of people with haemophilia, as set out in the charity's Articles, which define its charitable purpose. During my tenure as CEO, I had regular contact with the specialist haemophilia doctors and nurses in the Haemophilia Centres in

NHS hospitals. This might come about through meetings with their own member organisations e.g. the UKHCDO or the haemophilia nurses group and through the involvement of some of them in the Society's own Health Sub Committee and the joint Haemophilia Alliance. This was not necessarily 'with the purpose of disseminating information'. However, I mention this because in my experience communication was a two way process between the Haemophilia Society as the patient organisation, its staff and board, and the specialist healthcare professionals involved in providing treatment and care for our members and their families. See further on this in the next section on the Medical Advisory Panel.

6.1 The Medical Advisory Panel (MAP)

*Question 22: 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. [**HSOC0023999** and **HSOC0023961** may be of assistance].*

86. I have reviewed documents **HSOC0023999** and **HSOC0023961**.

87. As CEO, in 1999, I carried out a review of the MAP and made a series of recommendations about its future role in my report to the trustees on 25 March 1999 [reference document **HSCOC0023999**]. At that time, the MAP had not met for at least two years, and it was not the purpose of my review to consider the past history of MAP prior to my joining. I did not conduct a 'look back' exercise and cannot comment on the past role of the MAP. The purpose of my report was to consider the future. In my report it is noted that MAP members were all haemophilia specialist doctors; most were Comprehensive Care Centre directors. My report lists the seven doctors who were the MAP members in March 1999. The panel was lacking nurses, clinical experts in HIV, HCV or other relevant specialisms, and professions allied to medicine such as physiotherapy. My first conclusion was that the membership could be expanded to include wider a multi-disciplinary mix of specialisms. I noted in that report that the panel was being used on an ad hoc basis by staff when queries arose about particular treatment issues or medical concerns.

88. My report proposed to the trustees the new multi-disciplinary membership of the MAP, and its future advisory role with formal meetings, to be held twice a year and for the remainder of the year as a virtual panel to be consulted as and when required. The proposed new MAP would be complementary to the role of the new Health Sub Committee, my report notes, and its role would be advisory only.

The trustee board adopted these proposals, I recall. This could be checked against the minutes of the Trustee Board meeting of 25 March 1999.

89. In July 1999, I provided a further report on the MAP to the Trustee Board meeting on 3 July (see evidence document **HSOC0023961**). That report lists for board approval the proposed membership of the MAP to be appointed after the AGM on 3 July 1999. To reinforce the intention to avoid duplication with the Health Sub Committee's role, it was proposed that the medical members of the Health Sub Committee would also sit on the MAP. The membership of MAP increased to 17 members representing a multi-disciplinary spread of specialists. I recall the board adopted these proposals, this could be checked against the board minutes of 3 July 1999.

90. Both my reports cited above stressed that the role of the MAP was advisory: whilst it might be asked to advise on particular issues, the responsibility for formulating and making policy would remain with the CEO and trustees. I cannot comment on whether this was a change from the past prior to my tenure. This advisory role contrasted with the Health Sub Committee of the Board, which had a formal role to make policy recommendations to the Trustee Board. It would not be the MAP's role to make policy for the Society, only to advise the board, CEO and staff as required. A key role of the MAP, as per my reports to the board cited above, was to comment on publications produced by the Society to ensure that publications would reflect best medical opinion at the time.

Question 23: How did the Haemophilia Society select members of the Medical Advisory Panel? What criteria were used, if any? How did membership change over time?

91. Membership of the MAP did change over time, as it was to be reviewed annually after each AGM by the Society's CEO and Board, according to my report to the Board cited above. The implementation of that annual review would be recorded in board minutes, which are held in the Society's archives. I believe that such a review of the membership would have been carried out as originally envisaged. Selection criteria, to my recollection, were not set out formally. Changes in the membership would have reflected the original intention to ensure a multi disciplinary spread of experts.

92. For further evidence I would refer the Inquiry to the Society's archives for copies of minutes of MAP and the Health Sub Committee from the Society and for minutes of the decisions taken annually by the Board from 1998 to 2004 regarding the MAP membership (contained in the Trustee Board Meeting Minutes 1996-2006 Book).

Question 24: Please clarify during your tenure:

(a) How was advice sought from the Medical Advisory Panel?

93. Advice was sought on an ad hoc basis as the MAP functioned mainly as a 'virtual panel'. The primary source of medical advice for the Society was the formal Health Sub Committee and not the MAP. The MAP members might be approached on a topic if the members of the Health Sub Committee were not able to cover it. I cannot recall any specific examples. The advice would be requested, as I recall, by phone, email or fax via the staff member involved e.g. the HIV worker or the HCV worker. Records of this may exist in the Society, but I do not hold any, nor am I aware of their existence.

(b) Who decided when advice would be sought?

94. To the best of my recollection, that advice might have been asked for by staff members in response to member queries or when compiling information material for members; by the CEO and Board on specific topics or by the Health Sub Committee. At the time of writing, I have not reviewed relevant minutes as stated above in order to provide evidence to support my recollection. Normally, the Health Sub Committee members would be the 'first port of call' and only if their members were not able to assist would a request be made to a member of MAP.

(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?

95. This would be on a case by case basis. For instance, if specialist advice was needed on HIV/HCV the MAP member with specialist expertise in this area would have been asked. Normally, I believe, that advice would be asked for by one of the Society's specialist staff in the course of answering a member query or compiling information resources. Sometimes, on a case-by-case basis, it might have been relevant to ask several members to advise on a specific issue. I cannot recall any specific examples as this work was undertaken by members of the staff team and not by me as CEO.

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

96. To the best of my knowledge, the MAP members might discuss matters at their formal meetings (twice a year) or informally between meetings when the panel might be asked for input by fax and email. I cannot give any further information from memory.

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

97. To the best of my knowledge there was no MAP member who was more influential than the other members. There is no indication in my original proposals to the board about the MAP of any formal hierarchy within the panel; the intention was to achieve a sufficiently diverse spread of expertise and knowledge within the membership and not give higher status to one type of member over others.

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

98. As noted above, there was ad hoc communication with the panel between the formal meetings, so it would be expected that some matters were discussed outside the two meetings held each year. That expectation was set out in my reports to the Trustee Board cited above which proposed the MAP would be a 'virtual panel' to be consulted on an ad hoc basis when needed.

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

99. Advice might be communicated via the formal meetings, which would have had agenda, and minutes, via two way communication with the Health Sub Committee and in direct responses via phone, email or fax to ad hoc queries by staff or board members. I cannot recall the detail of how this happened in practice day to day during my tenure.

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

100. Records would exist in the form of minutes of formal meetings. I am not able to provide evidence of how responses to ad hoc queries were recorded by staff. It is likely that these might have been kept as file notes by staff members, possibly mentioned in reports by the specialist workers. I do not recall any particular change during my tenure to the way this work was conducted. If advice received was for the purpose of commenting on the content of publications, this would have been reported at the time, and it was customary to record a credit on the publication to the individuals who had contributed. So, for example, the publication titled *Hepatitis C the facts: routes of transmission* published November 1996 cite Nigel Hughes and Dr Charles Hay for their contribution to the factsheet. Both were members of the MAP. Unfortunately I cannot locate a copy of this factsheet, but the Society may have this.

101. The scope would include general haemophilia treatment issues, HIV/HCV, physiotherapy, orthopaedics, hepatology, nursing care, paediatric as well as adult care and treatment. Members of the MAP had expertise in all these areas.

(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?

102. I do not recall any specific examples of the Society seeking the advice of the MAP, nor what that advice was (if any).

Question 25: As far you can recall, please describe:

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

103. The remit of the MAP was advisory only, as per my reports to the board cited above. Those reports make clear that policy formulation was the remit of the Trustee Board, and that decisions might be informed by recommendations from the Health Sub Committee, a formal committee of the board. From my report to the board 3 July 1999: …*"whilst the MAP might be asked to advise on particular issues, the responsibility for formulating and making policy decisions would remain with the CEO and Trustees."* [**HSOC0023961**].

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

104. I am not aware of any examples of times when the Society did not follow advice from the MAP.

(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:

105. I am not aware of examples of times when the members disagreed with the chair of the panel. When originally formed the MAP had no chair.

(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:

106. I am not aware of any examples, relevant to the Inquiry's Terms of Reference, of when the Haemophilia Society did not follow the advice of the Chair of the MAP. As mentioned earlier, the MAP had no formal role and there was no chair.

Section 7: Relationship with the Government

Question 26: 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?

107. To answer this question fully, I would need to refer to all the detailed records held by the Society for 1998 to 2004. As CEO I was a main point of contact, and would have attended many meetings along with our chairman and sometimes other trustees. Generally, those meetings were at the Society's request in connection with issues we were raising such as through our campaigns. They were not regular, and tended to be ad hoc. During my tenure, the Society retained a public affairs consultancy, Weber Shandwick, for some of that period, and staff of the agency were active in building relationships with Government ministers, politicians and civil servants in order to advance our campaigns. Weber Shandwick replaced the Myriad agency from 1 March 2001.

108. In my capacity as CEO, leading on advocacy and campaigns which had the intention of influencing Government policy, frequent ad hoc meetings would have taken place with Government ministers, politicians, Department of Health Officials. Purely from memory, I believe a meeting once a month might be typical as an average, but there might be times when no meetings took place or maybe one or two more. I refer to the majority of the 55 documents from Haemophilia Society archives provided to me by the Inquiry's legal team: most of these relate to public affairs activities (i.e. they are about meetings held individually with politicians, including Ministers, and with groups of politicians – all party groups for instance).

109. During my tenure, I would say that the majority of my time was devoted to public affairs activities relating to the Society's advocacy on behalf of our members. Documents from the archives are likely to show letters to members of all political parties at Westminster and the devolved bodies, reports of meetings held with Ministers, some being internal reports to members and Board, others published in bulletins and in press releases. As CEO, those documents would show that I was involved in most of such meetings, and would often lead as spokesperson for the Society. As stated above, we also retained a public affairs agency for some of the time I was CEO, who might have made contact. The Bulletin carried reports of such meetings, and is probably the primary source of evidence along with the HCV campaigns newsletter. I do not hold any documents myself, and the Inquiry would need to refer to the Society's archives.

Question 27: Please describe the extent of your role and involvement with regard to the Society's interactions with and representations to the Government.

110. My role as CEO would be to represent the Society's policy position and to present the arguments and evidence for our campaign objectives. I had meetings with health officials that were related to specific interventions, such as response to product recalls and to the risks of vCJD. To my recollection, I would not attend such meetings alone: a board member and possibly a staff member (such as HCV worker) might be present. If a board member was involved, the chairman would be the most likely to be the one.

Question 28: 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:

111. Given the frequency of such meetings as a core part of my role as CEO over a six year period, I cannot recall specific detail of each and every meeting held. As stated earlier, I believe an average of one a month might be typical. I refer the Inquiry to the archive documents which related to this activity: it is possible that file notes exist of some such meetings, I do not hold any. Reports of this activity can also be found in the Trustee board minutes and in various communications to members over the period 1998 to 2004. In pursuing the Society's campaign objectives, it should be noted that professional public affairs agencies were retained by the organisation to build political support. These were Myriad and then Weber Shandwick. This involved very active campaigns to build and contact with politicians of all parties in support of the Society's campaigning objectives. Another source of information in this area, therefore, would be the reports from those agencies on meetings held. Some meetings were initiated by Government when matters arose where the input of the patient organisation, the Society, was needed, for instance on treatment supply issues or response to vCJD.

(a) How often did such meetings take place?

112. Frequently as noted above, and constantly. As stated earlier, I believe an average of one a month might be typical. Some meetings were initiated by the Society in pursuit of our purpose, others might be initiated by Government officials.

(b) Who did you meet with?

113. Politicians of all parties, at Westminster and devolved bodies, civil servants. Some were serving ministers: this would be reported in the member publications, such as the Bulletin and campaign updates.

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

114. Meetings were not always formally minuted, some were followed up by a letter from me or the chairman which summarised the key points of discussion. Formal meetings with a Government minister, I believe, would have been minuted by a civil servant. This might need to be checked with Department of Health officials and civil service archives over the period. The Inquiry would need to ask the Society if they hold any meeting records: I do not.

(d) What were the purposes of the meetings?

115. Meetings were held in pursuance of the Society's campaigns on HCV and HIV, for safer treatment and provision of recombinant, on emerging issues such as VCJD and supply of recombinant. The purpose was to get the government to take action on the issues we were campaigning on (described in later sections). This was central to the advocacy role of the Society as a membership organisation seeking the best possible treatment and care for people with haemophilia.

(e) What was discussed at the meetings?

116. Discussions would be related to the issues current at the time, which will have varied over the six year period when I was CEO and I have mentioned the main themes immediately above. The Society would be attending such meetings, represented by me and often the chairman or other board members, to represent the interests of our members and speak on behalf of the patient group. Our focus would derive from the charity's purpose to secure the best possible treatment and care for people affected by bleeding disorders and to achieve justice for those infected by contaminated blood.

Section 8: Campaigning

8.1 Hepatitis C campaign

*Question 29: The Inquiry is aware of the Haemophilia Society's Hepatitis C campaign [you may be assisted by **HSOC0026341, HSOC0022985** and **HSOC0016621**]. Please explain giving as much detail as you are able:*

(a) Why the society launched the campaign, including any particular events which prompted it;

117. I have reviewed documents **HSOC0026341**, **HSOC0022985** and **HSOC0016621**.

118. When I joined the Society as CEO in April 1998, the Society had already been campaigning for some time on Hepatitis C (HCV) and was working with the special interest group the Manor House Group. The Society's HCV worker Lucy McGrath was heavily involved in supporting the long-running campaign, and this was a major focus for the Trustee Board. A campaign group had been formed already. Having been recruited for my background in advocacy and campaigns, as CEO I was expected to play a key role from day one in taking forward the HCV campaign. Given this background, and the sense of urgency to press forward with the campaign, as CEO my role was to lead action. There was a degree of anger and frustration at that time, voiced strongly by the Manor House Group and by board members affected by HCV, at the perceived injustice felt by people with haemophilia who had been infected with HCV and had received no recognition of this harm from Government and no financial assistance. This was a very emotive subject.

119. For background regarding the history of the HCV Campaign, I cite the HCV Campaign Update October 1998 [**HSOC0014399**]. This publication sets out the history of the HCV Campaign from March 1995 when the Society launched it. Also set out is the future action plan for the HCV campaign, which involved new strategies and a wider scope of action.

(b) The aims of the campaign;

120. The aims of the long running HCV campaign are well explained in documents relating to my first month in post as CEO. In my first week as CEO on 1 April 1998 I represented the Society at a meeting arranged by Roger Godsiff MP to address the concerns of the people infected with HCV. I cite the internal memo written by Lucy McGrath in advance of that meeting [**HSOC0000313**] which sets out clearly the HCV campaign objectives at that time: to draw attention to the impact of HCV infection on people with haemophilia, and to make the case for 'recompense'. The intention was to engage MPs in support, as can be seen in the briefing document.

121. In July 1998, this was followed by a 'Day of Action for Hepatitis C Victims'. The press release [**HSOC0009365**] sets out very clearly the campaign messages and I refer to that as evidence: key messages are the deaths due to HCV, the impact of the infection on the lives of those infected and the injustice in lack of recompense and support from Government. We presented a petition to the Prime Minister, held a mass lobby at Westminster of HCV infected people, and demanded a response from then Health Secretary Frank Dobson. Prior to my joining the Society, in September 1997, the chairman

and other representatives had met with Mr Dobson to press the case for justice, and a response was still awaited in July 1998 when the Day of Action took place.

122. Later that month, the Society received a negative response from Government, which was a huge disappointment, and this prompted a review of the campaign by the Trustee Board. My memo of 30 July 1998 to the Board [**HSOC0013933**] proposed a review of the campaign strategy, noting that the long-running campaign had not achieved success with two Governments, Conservative and Labour. In effect, this was a recognition that there needed to be change in the way the HCV campaign in future.

(c) Whether those aims changed;

123. During the six years of my tenure as CEO, the HCV campaign was reviewed several times by myself and the Trustee Board. Given the high priority accorded to the HCV campaign, and the level of resources committed by the charity over such a long time to the campaign, it was essential good governance that the Trustee board and the charity's CEO should undertake regular strategy reviews.

124. The first such strategic review took place in September 1998, following the Government's rejection of our call for financial assistance for people infected with HCV. My report to the Trustees meeting 25 September 1998 'Hepatitis C Campaign: future directions' [**HSOC0016864**] should be read in full in addressing the question as to whether the campaign aims changed. The campaign for financial assistance for those infected with HCV had failed to persuade a Conservative and then a Labour Government, and this was a serious setback. As the report states, the campaign until then had been based on the moral argument; the report proposed a fresh strategy, broadening the scope, and re-launching a fresh campaign.

125. A further strategy day was held on 27 November 1999 to discuss the future of the HCV campaign, (see notes of the Trustee Bard Awayday 27 November 1999: **HSOC0029689_029**).

126. There was another HCV campaign review meeting on 11 September 2000, and there was further discussion in 2001, at which time the campaign aims were revised. The campaign review initiated then was comprehensive and involved consultation in 2000 with our membership. See consultation letter from me to members August 2000 The Hepatitis Campaign: Tell us your Views [**SCGV0000172_061**].

127. Minutes of the Trustee Board meeting 11 September 2000 record the outcome of that review, which was to define the aims of the campaign as follows:
    - To persuade government to provide financial assistance to meet the needs of all people with haemophilia and related bleeding disorders affected by HCV
    - To press for the best treatment and care for people with haemophilia and related bleeding disorders infected with HCV
    - To persuade government to hold a full public inquiry into contaminated blood products
    - To ensure recombinant is available for all throughout the UK regardless of age of viral status

128. During that year, a memo from me to the Trustees dated 14 December 2001 [**HSOC0029689_042**] raises concerns about funding the campaign, and in 2002 there was discussion of lower cost options for the campaign.

129. I hope this answer gives a sense of the continued commitment by the Board and myself as CEO to the aims of the campaign during my six years in post and of how major a focus this was for the whole organisation. In that context, I believe we all understood that the campaign aims were going to be extremely difficult to achieve. This was made clear to me as CEO in my first few months in post in 1998 when Government rejected our call for financial recompense. As stated above, this was a major setback, and it was apparent the HCV campaign would need to be modified as approaches followed to date had not succeeded.

130. During my time in post, the HCV campaign was reviewed and modified at different points in light of changing circumstances, starting from 1998 as explained below. As the charity's CEO, I was very mindful that the Society's resources were not limitless, and the strategic reviews by the Trustee Board of the campaign during my tenure were intended to ensure that best use was made of the resources available for the HCV campaign.

(d) Who was responsible for the campaign;

131. Responsibility for the campaign lay with the Trustee Board. As CEO my responsibility was to advise and support the board on campaign strategy, and to lead implementation of the campaign strategy set by the Board. As Trustees, it was the responsibility of the Board to decide priorities for the charity and to determine the appropriate use of the charity's resources, both in terms of staff and in terms of direct expenditure on advocacy and

campaigns. As stated above, the HCV campaign was long running when I joined in 1998, and considerable resources had been expended already. This formed background to the review initiated in 1998.

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

132. To address the question of the actions taken by the Society to further the campaign, the best reference would be to the minutes of board meetings, which list activities/actions and also the Bulletin and the HCV campaign newsletters. These are archive documents of the Society. Those documents would provide evidence and set out the detail of the campaign year on year between 1998 and 2002 when I was CEO. From day one in post in April 1998, as CEO, as mentioned in earlier answers, the HCV campaign was high priority and this remained the case until I left in 2004. Action was continuous and sustained, involving a huge range of campaigning tactics and expenditure on staff time, and on external PR/public affairs agencies.

133. The December 1998 issue of the HCV Campaign Update, which we produced for our members [**HSOC0021235**], shows the huge effort committed. This, and future issues of the HCV Campaign Update and the Bulletin, provide evidence that the Society's HCV campaign was constant and a huge part of my role as CEO of the kind of we engaged our membership in. I do not hold copies of such publications, but have reviewed the ones provided to me by the Inquiry. This effort included campaign activity at grass roots; we lobbied politicians at Westminster and the Scottish Parliament; we used press and media to raise the profile of our campaign, we built up an influential supporter base at Westminster and the Scottish Parliament. An example of a grass roots campaign would be the Carpet of Lilies. The intended impact of this campaign was to secure support from local constituency MPs for the aims of the campaign. We were advised that local MPs tend to be responsive to approaches from their own constituents and therefore that local Society members might play an active role in seeking support from their own MP. At the time I left the Society, we had achieved a number of breakthroughs after six years of concerted action. The future campaign would build on this. At that point, the government was on the verge of implementing a financial assistance scheme for HCV and was rolling out recombinant: significant achievements in terms of our aims.

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

134. Referring to my report to Trustees of 25 September 1998 [**HSOC0016864**] cited above, this document sets out clearly the strengths and weaknesses of the campaign, and the obstacles faced. Those obstacles were financial, as the charity's resources were over-stretched, but also included internal tensions and divisions, lack of legal 'muscle' and low public awareness of hepatitis C and its impacts. Both of the latter issues contrasted with the situation relating to HIV; when the Government was forced to provide financial assistance for HIV infected people with haemophilia due to (a) pressure from legal actions; and (b) the (very much higher) profile of HIV, and number of deaths associated with it.

135. It was clear that the HCV campaign faced very considerable obstacles, and this was very difficult for the Society as a membership organisation as it was a hugely emotive subject. The frustration and anger, the sense of injustice felt by those who had been infected, and their families, were acute. Sometimes these did break out in the form of internal arguments and disagreements; there was a great deal of anger and pain within our membership and this very much affected the Society, its trustees and me as the CEO. There was a strong sense of injustice and unfairness amongst many members, and disagreements arose relating to this. There might be disagreements about how to conduct the campaign, how long to carry on, whether the charity could afford to maintain the campaign at the level of expenditure, for instance. For example, in December 2000, concerns were raised by me about the decision to commit an additional £100k to the campaign, in circumstances where £230k had already been spent. Personally, as CEO, I felt determined and motivated to continue the campaign on behalf of all those affected, whilst also recognising that the obstacles were considerable and our resources were limited.

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

136. I do not think the Government gave any assurances that would cause the Society to change our campaign. The campaign continued over the six years of my tenure and we had to keep campaigning because the Government response was negative. As mentioned above, in my first year the Government rejected our campaign for recompense. We changed our approach to the campaign, not because of any assurances from Government, but in order to improve our chances of winning. It would have been pointless after the first major setback in 1998 to continue the campaign as before. Hence, the strategic reviews referred to above, of the campaign's aims and approaches. We kept fighting, but we had to modify our battle plans and means of attack, if we wanted to win. As stated earlier,

during my tenure the future of the HCV campaign was reviewed at least three times by the Trustee board and myself.

137. This resulted in modifications to the way we approached the campaign. A significant milestone was the decision by Board to invest in a new campaign and appoint Weber Shandwick as the new agency to support the campaign.

138. For evidence see the Bulletin Autumn 2001 issue 3 [**HSOC0023043**] which is almost wholly dedicated to news of the campaign, and extensive action on a number of fronts. This issue also indicates the start of the important breakthrough in Scotland, due to the efforts of the Society and its members in Scotland, to target the Scottish Government and members of the Scottish Parliament (MSPs). I also refer to the press release issued 9 September 1999 [**HSOC0014010**] Haemophilia Society delegation meets with Health Minister on Hepatitis C. The news release is about meeting with the Scottish Minister Susan Deacon MSP, and this Scottish phase in the campaign was to lead to our first significant breakthrough in the HCV campaign.

139. On 20 March 2002 the Trustee board minutes [**HSOC0029689_043]** record discussion of the report of the HCV Think Tank which had been formed to develop proposals for a financial scheme modelled on Canada's. The plans to present this to Government were discussed.

(h) Whether the Haemophilia Society achieved its aims;

140. When I left the Society in 2004, we had achieved some of our campaign aims, but not all. I note that the Society continued to campaign after that point, and might be still seen as campaigning now. A statement published by the Society's Trustees on 14 March 2017, some 13 years after I had left, shows that the campaign for justice on behalf of those infected by contaminated blood products remained live. At the time when I left, the matter of the proposed ex gratia scheme was still under discussion, and details were yet to be resolved. So I would say that the achievement of those aims was still a work in progress.

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

141. The Society's campaign is ongoing, I believe. The public inquiry taking place now represents a significant achievement in my opinion, as this was one of the aims of the campaign when I was in post.

(j) If not, what the result of the campaign was

142. Recent political announcements suggest that a further breakthrough may be imminent; however, this is not clear at the time of writing. At the time I left, we had achieved progress on securing recombinant treatment for all which was being rolled out through the NHS and on a financial assistance ex gratia payment scheme for HCV. We had not persuaded Government to commission a public inquiry.

8.2 Campaign for recombinant blood products

*Question 30: The Inquiry is aware of the Haemophilia Society's campaign for recombinant blood products. The following document may be of assistance: [**MACF0000006_118**]. Please explain, giving as much detail as you are able:*

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

143. When I joined the Society in April 1998, the campaign for recombinant treatment was already well established. It was a campaign supported by both patients and clinicians, which was driven by concerns about the safety of plasma products, partly because of the experience of HIV and HCV infection through contaminated products, and also because of the risks of other blood borne viruses and of vCJD. Government had already, prior to my joining, taken the decision that recombinant would be provided for under 16s due to the so called 'theoretical risk of vCJD'. The focus of the campaign was to extend that to all patients.

144. The rationale for the campaign was well established: in 1996, the UKHCDO had recommended that recombinant should be treatment of choice for haemophilia in order to minimise the risks of blood borne viruses or other infections agents. There was public concern at the time about the safety of blood and blood products, heightened by the emergence of new variant CJD, a very alarming and fatal condition for which there was no screening test. The latter point is very significant: prevalence of vCJD was unknown in the absence of a test, and it was not possible to screen patients to see if they had vCJD. Even if detected, there was no treatment available for vCJD. In 1998 the Government acknowledged the 'theoretical risk' that vCJD might be transmitted in blood products and decided that the NHS should switch all children under 16 years to recombinant. Also in 1998, the Government's own blood products facility, BPL, was required to stop the use of British plasma and switch to US plasma, as no cases of vCJD or BSE had been identified in the USA. That was the situation when I joined the Society.

145. The aims of the recombinant campaign relate to the primary mission of the Society, to secure the best possible treatment for people with haemophilia and related bleeding disorders. This meant seeking the safest treatment: recombinant was the treatment of choice of clinicians. For reasons of cost and supply, recombinant was not being provided through the NHS for all patients. This made the Society's campaign for recombinant for all urgent and compelling in the context of a patient group which had experienced 'the worst treatment disaster in the history of the NHS' (a phrase which will be seen widely quoted in so many communications by the Society and those supporting our campaigns) through infection with HIV and HCV. This can be seen in the Bulletin and campaign newsletters for example, issues 1 and 2 for 2001 [**HSOC0023040**; **HSOC0023041**] which feature news on recombinant. With this history, the rationale for the campaign for recombinant is obvious. So many had already died, and others were seriously ill through HIV and HCV, and now this same patient group faced the unknown but very concerning risks of vCJD. This explains the urgency of the Society's campaign seeking recombinant treatment for all patients with haemophilia. This was perceived by patients and clinicians as the safest form of treatment. In 1998, therefore, the campaigns for recompense for those affected by HCV went hand-in-hand with the recombinant campaign. See Bulletin 1998 Issue 4 [**HSOC0023024**] talks about the two campaigns as equally important.

(b) The aims of the campaign;

146. At the time when I joined in April 1998, a significant breakthrough had been recently achieved, as in February 1998 the Government announced that recombinant would be provided for all previously undiagnosed people with haemophilia under 16 years, acknowledging the safety concerns put forward by the Society.

147. The clear aim of the campaign was recombinant for all, adults and children alike, throughout the UK. At that time, recombinant was still a relatively new treatment product, and was available only for Factor VIII; Factor IX was still in development until 1999. So key issues for the campaign were to press for extension of recombinant treatment for all age groups and for availability of Recombinant Factor IX. Supply was a major concern at the time, as this was such a new product. This was evidenced in the letter from then Health Secretary Philip Hunt 31 January 2001, which mentions the worldwide shortage of recombinant [**HSOC0002190**], as well as in the Bulletin 1999 issue 4 [**HSOC0023026**] which updates on the recombinant campaign (and ongoing recombinant shortages) and the survey commissioned by Dr Linda Garvican of provision of recombinant in the NHS in England, Scotland and Wales [**HSOC0023026**]. Bulletin Autumn 2000 – Haemophilia

Alliance national specification. These documents demonstrate achievement by the time I left of the provision of recombinant for all – this was in progress – and the impact of supply shortages on the intention of supplying recombinant for all patients.

(c) Whether those aims changed and, if so why;

148. I would say the aims of the campaign remained the same during my tenure: to achieve recombinant treatment for all patients. Campaign tactics and strategies changed in response to developments, as the campaign was incremental in the sense that along the way breakthroughs were achieved that we were able to build on. For evidence I cite two issues of the Society's member newsletter: Spring and Summer 2001 issues of the Bulletin [**HSOC0023040** and **HSOC0023041**]. These give a sense of the political nature of the campaign: we had to persuade politicians to make available the funding to make recombinant available to all patients, and this was achieved in stages. At that time, 2001, the Society reported to its members [issue 2, summer 2001: **HSOC0023040**] that we were still awaiting a firm commitment from Government to extend recombinant to all as swiftly as supplies allowed. The latter point reflects the supply shortages which were another obstacle to making recombinant universally available through the NHS. My editorial (page 2) states *'…we want a firm commitment from Government now to the principle of providing recombinant for all – and a pledge to phase in recombinant as rapidly as supplies allow. This will remain one of the Society's main campaigning aims until that policy is implemented…'*

149. In 2001, when the Society re-launched its campaigning and engaged Weber Shandwick Public Affairs agency to support the campaign, it is important to note that the aims were combined into a single campaign. So [refer to Bulletin Summer 2001 issue 2: **HSOC0023041**] the aims became:
    - Recombinant for all children and adults throughout the UK to avoid the risks of future blood borne infections;
    - A public inquiry into the tragedy of contaminated blood products that infected people with haemophilia with HIV and HCV;
    - Financial recompense through a hardship fund for people with haemophilia infected with HCV in addition to the financial assistance scheme established by Government in 1987 for those infected with HIV (the Macfarlane Trust).

150. This meant that we were then fighting one integrated campaign - and not three separate campaigns. This was a logical change as the origin of all these campaign aims was the

same: the disaster of HIV and HCV infection through infected blood products, and the risks of future blood borne infections.

(d) Who was responsible for the campaign;

151. Operationally, as CEO I was responsible for the delivery of the campaign, together with other members of the staff team, and the PR agencies the Society contracted with during my tenure. Ultimate responsibility lay with the Trustee Board, as the governance body for the charity, and I was accountable to the board.

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

152. During my tenure, the recombinant campaign was a huge focus for the Board, our members and staff. It was a campaign in which we joined forces with clinicians, as haemophilia doctors wanted recombinant to be the treatment of choice for their patients. See Bulletin spring issue 1 2001 [**HSOC0023040**], which reports that the UKHCDO and Haemophilia Nurses Association were with the Society in calling for urgent action from Westminster Government to implement recombinant for all, which was already policy in Scotland and Wales at that time.

153. The actions taken included applying pressure through press and media, through political and parliamentary methods such as debates and parliamentary questions, through members contacting their own MPs, meeting with Ministers at Westminster and devolved bodies. As shown in the letter, which was sent to registrants' Health Authorities [**MACF0000006_118**] some of the Society's individual members took their own action in refusing plasma-derived treatment and I wrote to the relevant health authority to ask them to fund recombinant for that patient. The letter pointed out the huge cost to the individual patient in refusing treatment, given that haemophilia can be life threatening if untreated, and 'potential risk to his life to make the points that he deserves and needs the safest possible treatment.'

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

154. As stated earlier, the obstacles were cost and supply of recombinant. The main challenge was political: to persuade the Government to adopt the policy of recombinant for all, and to make the funding available to achieve that. I am not aware of internal disagreements being an obstacle on this campaign.

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

155. As stated above, the Government had already begun to respond to the pressure of our campaign in 1998, when it decided to make recombinant available to patients under 16 years. I am not sure what is meant by the use of the term 'assurances' in the context of this campaign. The fact was that the Government could not give the patients or their clinicians any assurance of the safety of blood products once they had acknowledged the 'theoretical risk' of vCJD. Our campaign aimed to maintain the pressure to act by making recombinant treatment available to all. Over time, we were able to persuade Government to commit the funding to supply recombinant for all: this was due to our persistence and our determination to carry on the campaign until it achieved its aim.

156. Over my tenure, there were changes in the way we ran the campaign but I do not think these were related to any 'assurances' from Government. More it was a question of making incremental changes in tactics and strategies in response to changing circumstances and as breakthroughs were achieved. The aims of the campaign were consistent: we were always clear that recombinant for all was the goal. If a timeline were produced for the recombinant campaign during my tenure 1998 to 2004 it would include milestones along the way when there were breakthroughs e.g. when recombinant for all was adopted in Scotland and Wales. The campaign built on those breakthroughs tactically – so once recombinant was being provided for patients in Scotland and Wales, that gave us a stronger *argument* to persuade Westminster to do the same for patients in England. To answer the question, I do not think it would be true to say that we changed our approach.

(h) Whether the Haemophilia Society achieved its aims;

157. When I left the Society, I would say that the aims of the recombinant campaign were achieved. The Government had agreed to provide recombinant; the roll out was due to start on 1 December 2003. Issues after then were to do with logistics of supply, as I recall. The political argument had been won.

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

158. As stated above.

(j) If not, what the result of the campaign was

159. The campaign aim of recombinant for all was achieved.

Question 31: Do you know what the outcome was from Chris Hodgson's complaint (via Lord Morris) to the Parliamentary Ombudsman in relation to possible maladministration as a result of the provisions of recombinant to patients in England [HSOC0012668]? If you are aware of the outcome, please set out in as much detail as possible.

160. As far as I can recall, the Ombudsman did not investigate whether maladministration had occurred on the basis that this was out of the remit of the role. Apparently the Ombudsman had no power to question Government policy and, although I note that Chris Hodgson wrote on 25 February 2003 to ask Ms GRO-D to reconsider her decision, as far as know this did not happen. At that time, the Government did announce that it was making £88 million available to provide recombinant to patients over 21 years, which was a breakthrough for the Society's campaign to secure this safer treatment for our members. I believe that we may have decided that there was no further purpose in pursuing the Ombudsman and that we would need to adopt other tactics to persuade Government to address the contaminated blood disaster of the past.

8.3 Campaign for financial assistance

Question 32: The Inquiry is aware of the Haemophilia Society's campaign for financial assistance [HSOC0000313, HSOC0000307, HSOC0026345, HSCO0026349, HSOC0026358, HSOC0016872, HSOC0016873, HSOC0000206, HSOC0009365, HSOC0013933, HSOC0016864, HSOC0014399, HSOC0021235, HSOC0019683, HSOC0014010, HSOC0029689, HSOC0002038, SCGV0000172_061 and HSOC0003277 may be of assistance]. Please explain, giving as much detail as you are able:

(a) When and why the society launched these campaigns, including any particular events which prompted it;

161. As stated above, the Society's campaign for financial recompense for HCV was well established and long-running when I joined as CEO. In my first month, I attended a meeting on 1 April 1998 with MPs to advance the campaign for recompense for those affected by HCV. See briefing document **HSOC0000313**.

162. The arguments which formed the basis for the campaign (which were sometimes called 'the moral' arguments) are set out in the document. The impact of HCV infection on people with haemophilia, medical and social, had not been addressed by Government in the form of financial assistance, unlike the impact of HIV on the same patient groups, similarly infected by blood products. A follow up letter from me to Roger Godsiff (MP) [**HSOC0026345**] repeats the 'moral argument' stressing the lack of equity in the

Government providing financial assistance for those infected with HIV and not also those infected by HCV. The argument was pursued through Westminster: see the Lords debate on 13 May 1998 initiated by Lord Alf Morris titled '*What is the Government doing to assist people with haemophilia infected with HCV?*'. [**HSOC0000307**].

163. A detailed response to points made by the Government Minister Baroness Ramsay 5 June 1998 sets out in full the Society's arguments, and gives a clear indication of the political context in terms of the stance adopted by Government: [**HSOC0016872**].

(b) Their aims of the campaign;

164. In the press release dated August 2000 [**SCGV0000172**] I set out the aims of the campaign as being:
    (a) To persuade Government to provide financial assistance to meet the needs of people with haemophilia or related bleeding disorders infected with HCV;
    (b) To keep the issues of HCV infection through contaminated blood products high on the public and political agenda;
    (c) To press for best treatment for people with haemophilia and related bleeding disorders infected with HCV
    (d) To raise public and political awareness of HCV.

(c) Whether those aims changed and, if so, why;

165. We reviewed our campaign aims during the time I was in post, but they remained essentially unchanged. Financial assistance for people infected with HCV was a main aim when I joined and remained throughout.

(d) Who was responsible for the campaign;

166. Ultimately the responsibility lay with the charity's board of trustees. Operationally, in terms of managing the campaign, that responsibly was with me as CEO.

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

167. During my tenure we took constant action to further the campaign. It was high priority when I joined and remained so throughout. We used every sort of campaign tactic: press and media, political lobbying, grass roots campaigning to keep up the pressure on Government. Clearly, the Society committed considerable resources to funding the campaign, and the Bulletin reports over my tenure, continuous action. We also sent a

regular HCV campaign update to members, quarterly I believe, to show the many actions in play at the time.

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

168. There were considerable obstacles. I would say most of these lay outside the Society, rather than within. At times there were disagreements within our organisation about how to conduct the campaign, and considerable frustration that we had campaigned for so long without success. But the primary obstacle was the Government.

169. In July 1998 the Government refused the Society's call for financial assistance. An indication of the obstacles we faced can be seen in my memo to trustees dated 30 July 1998 [**HSOC0013933**] which refers to the decision, noting it was taken at the highest level, involving 10 Downing Street, and full Cabinet. The memo notes this decision as a major setback: the Society's appeal for financial assistance had been rejected by both Conservative and Labour Governments. This prompted a review and fresh thinking within the Society about the campaign: the HCV campaign bulletin in October 1998 sets out new campaign strategies and tactics. It is clear in saying the Society was not giving up on the HCV financial assistance campaign and planned to fight on [**HSOC0014399**]. However, this document also shows a wider range of aims for the HCV campaign beyond financial recompense: including provision of support services for those with HCV, action to address problems with insurance and mortgage and the call for a public inquiry. The December 1998 issue of the HCV campaign update [**HSOC0021235**] provides further evidence of these strategies in action. This sets out the four aims as defined then following the strategy review: to persuade Government to provide assistance for those infected with HCV; to keep the issues of HCV infection through contaminated blood high on the agenda; to press for best possible treatment for HCV; and to raise public and political awareness of HCV.

170. Taking the opportunity offered by devolution, the campaign in Scotland gained momentum, and the impact of the Scottish members campaign for HCV can be seen in press release for 9 September 1999, when I attended a meeting with the Scottish Health and Social Care Minister Susan Deacon MSP.

171. My statement in the press release [**SCGV0000172_061**] sets out the broader aims of the campaign at that time, financial recompense being included alongside the call for an inquiry, proper tracing of those infected with HCV and treatment and care.

172. As the campaign went on, as stated in earlier answers, the Trustee Board periodically reviewed the future and asked the question whether the efforts should continue. See the August 2000 consultation with members 'The Hepatitis C Campaign: tell us your views' [**SCGV0000172_061**].

173. To my recollection, there would have been disagreements about how long to carry on, how best to conduct the campaign, and how much to spend. This involved robust discussions within the board; minutes show this and that decisions were taken by the board notwithstanding differences of opinion.

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

174. As stated previously, during most of my tenure the Government response to the campaign for financial assistance for HCV was negative and in July 1998 the Government refused the Society's call for financial assistance. The Society decided to keep on campaigning nevertheless. For most of the time I was in post, we were campaigning in the face of negative responses from Government and only in my last months in post was there a shift when Government finally conceded and began to make moves towards setting up an ex gratia scheme. We were not given any assurances at all by Government that they intended to address the demands set out in our campaign until that change of mind in 2003 when the Government agreed to set up an ex gratia payments scheme for HCV. For reference see my final report to the trustee board 30 March 2004: **[HSOC0029689_054]**. At the time I left, the Government had agreed to provide an ex gratia payment scheme for HCV, and the Society was responding to this. We did not believe it went far enough, and were arguing for improvements e.g. to include payments to widows and families.

(h) Whether the Haemophilia Society achieved its aims:

175. When I left the Society in 2004, the Society had partially achieved its aims with regard to financial assistance. By December 2003, the Government had agreed to set up an ex gratia payments scheme for HCV. In due course this became the Skipton Fund. In parallel, there was a strategic review of the HIV assistance provided by the Macfarlane Trust, and awareness that there might be unmet support need amongst those co-infected with HIV/HCV. At that stage, I believe that there was a strong sense that the financial assistance schemes funded by Government did not fully address the impact of HIV and HCV infection by contaminated blood on people with haemophilia. They did not go far

enough. I recall – but cannot give specific examples – that levels of payments were seen as inadequate, and that wider support needs of people who were infected were not being addressed. The Macfarlane Trust was an independent entity, and had its own systems and processes for allocating grants. As CEO I was not involved in any way in that process and I held no formal role with the Trust.

(i) If so, when the Haemophilia Society achieved its aims:

176. As stated above, the Society partially achieved its aims with regard to financial assistance when I left the Society in 2004. However, the campaign continued after I left.

(j) If not, what the result of these campaigns were:

177. I believe much of this has been covered under the HCV campaign 8.1. At the heart of this issue in my time with the Society was the sense of injustice that the 'financial assistance' provided by Government to those infected with HIV was inadequate, and did not include those also infected with HCV. It was not seen as recompense. The settlement was seen to have been made under duress, with waivers being required, on the eve of court actions. The devastating loss suffered by the whole haemophilia community – including family, children, partners of those infected – was not compensated.

8.4 Other campaigns

Question 33: For any other campaigns relevant to the Inquiry's Terms of Reference which were organised by the Haemophilia Society, please explain, giving as much detail as you are able:

(a) When and why the society launched these campaigns, including any particular events which prompted it;

178. During my tenure, we campaigned on many issues affecting our members. Those relevant to this inquiry would be campaigns to ensure best possible treatment and care for those who had been infected with HCV/HIV. To my recollection, we campaigned for treatment for hepatitis (interferon and liver transplants) and on delays to knee replacement surgery for people with haemophilia. As a patient group, we addressed issues which our members brought to our attention and which might be raised by specialist clinicians. The clinicians might find that the funding mechanisms of the NHS were a barrier to being able to offer the best treatment to their patients e.g. a knee replacement would be held up due to lack of funding. These treatment issues would be raised and discussed through out Health Sub Committee and in discussions with UKHCDO and the Haemophilia alliance.

(b) Their aims;

179. This would depend on the specific treatment issue. So, where we identified difficulties in access to treatment, we picked up and addressed the specifics, either locally by targeting the NHS trust/health authority concerned or nationally via Department of Health.

(c) Whether those aims changed and, if so, why;

180. Our aim remained consistent: to secure the best possible treatment and care. The over-arching aim did not change but tactics and focus might.

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

181. External obstacles were: availability of funding through the NHS, the bureaucracy of the NHS, constant restructure of the NHS which changed the way treatment was commissioned were common obstacles faced when achieving the aims for all our campaigns. Internal obstacles would be resources: the Society was a small charity and funds were limited. The Trustees had to priorities the use of those resources to try to meet all the charitable objectives of the Society. I do not believe that internal disagreements were a significant obstacle on this.

(e) Whether the Haemophilia Society achieved its aims;

182. This is ongoing. I would say that during my tenure we were successful in raising the profile of haemophilia treatment, as a rare condition requiring very specialist treatment, and in having a voice within the specialist commissioning systems of the NHS. The NHS was subject to constant reorganisation during my tenure, and it was a challenge for the Society to keep pace with the change and ensure that the needs of people with haemophilia were considered in this context. I recall we were quite heavily involved in consultation with specialist commissioning groups in the NHS when I left the Society and would regard this as an achievement in the Society's aim of securing best treatment.

(f) If so, when the Haemophilia Society achieved its aims;

183. At certain points, we achieved breakthroughs, and those might be seen as achievements of aims. As treatments were evolving for HIV, hepatitis, surgery such as liver transplants and joint replacements, the Society during my tenure was active in campaigning to secure

access to the best for our members. The campaign for best possible treatment and care is timeless in a sense, as this is a changing field.

(g) If not, what the result of these campaigns were

184. The Society was campaigning throughout my time for the best possible treatment and care for all. This included addressing postcode lotteries (so called) by which level of service was not consistent for all and was dependent on where patients lived. The work with the Haemophilia Alliance addressed this through a national service specification and audit to achieve standards across all treatment centres. We also campaigned for access to treatment for HCV (interferon), surgery (liver and joint replacements) and best possible treatment for HIV. That work involved the development of the specification to set a standard that would be consistent, nationally.

185. In my time, treatments were evolving continuously and therefore the Society's campaign for best treatment and care evolved and its aims changed in light of changing situation with regard to clinical treatments being developed and the way treatment was provided in the NHS. The NHS was subject to change during my tenure: successive Governments decided to re-organise the NHS and the way treatment and care was funded, commissioned and delivered. The Society's campaigns had to keep pace and in a sense it was a constantly moving target.

Section 9: vCJD

9.1 BPL Product recalls, Products Incident & Patient Notification – vCJD

Question 34: The Inquiry is aware of product recalls by BPL between 1997 and 2000 following the UK Medical Controls Agency instruction in October 1997 to recall all vCJD implicated plasma derived blood products. Please explain, giving as much detail as you are able:

(a) The extent of the Haemophilia Society's knowledge of product recalls by BPL between 1997 and 2000;

186. I do not have sufficient recollection of the detailed sequence of events during this time to answer this, and can only refer you to the Society's archives and publications to members during my tenure. With regard to the Society's role, I have tried to give an overview in answer to this question. The Society is a charity and not part of the NHS or BPL, nor the regulator (originally the UK Medicine Controls Agency but which became the Medicines and Healthcare products Regulatory Agency in 2003) hence we had no formal role within

these statutory bodies. This meant that we would not have information on which NHS patients received specific batches of plasma product, and that information remained within the NHS, and specifically with the haemophilia centre doctors.

187. As a patient group, our concern was to ensure that members were fully informed of safety issues relating to their treatment. But we did not hold a statutory responsibility as we were not part of the NHS or Government agencies. We were able to use our own communications channels to make members aware of such incidents. In the Bulletin issue 1 Spring 2001 [**HSOC0023040**] I wrote: '*We believe strongly that patients (or in the case of very young children, their parents) have a right to be informed of issues such as this which affect* their *treatment…'*. This was in relation to the finding that a plasma donor had been found to have vCJD in 2000 and their plasma had been used by BPL to make haemophilia treatment products. We were reliant on BPL and statutory bodies to inform the Society of incidents such as this: we did not have an independent source of such intelligence.

188. We were clear in our principle as the national patient group, as stated above, that patients had a right to be informed. The Bulletin shows evidence of communications by the Society on treatment issues on an ongoing basis throughout my tenure. We wrote to members in January 2001 about the BPL incident, however, we were aware that we might not hold contacts for all patients on our database, as not all patients were members of the Society, and only the NHS held patient records for all.

(b) The extent of the Haemophilia Society's involvement, if any, in product recalls by BPL between 1997 and 2000;

189. The Society, as a patient organisation, had a role in providing information and communications to our members about the recall taking place. We were consulted, and our views on behalf of patients were invited. However, the Society is a national charity and is not a statutory body within healthcare, and we had no statutory role in product recalls.

190. With regard to the BPL plasma donor incident referred to above, the task of tracing patients who may have received affected product fell to the haemophilia centres. We coordinated, writing letters to members on our member database with letters and phone calls from the haemophilia centres to their patients. At that time, we received many calls to our Freephone Helpline from patients. In the Bulletin piece referred to above, I noted that many callers were angry to have been exposed to the 'theoretical risk' of vCJD after living through the tragedy of HIV and HCV infected blood products in the 70s and 80s. There

was also media publicity at the time, some of which may have been quite disturbing for patients and their families.

(c) The Haemophilia Society's view on the Department of Health/National Blood Authority's advice with respect to patient notification following the BPL product recalls between 1997 and 2000.

191. I cannot recall, after such time has elapsed since I left the Society, what the Society's view was on the Department of Health/National Blood Authority's advice with respect to patient notification following the BPL product recalls between 1997-2000.

Question 35: The Inquiry is aware of the situation in which BPL became aware in December 2000 that a plasma donor had been diagnosed with vCJD and in January 2001 notified the UKHCDO [Hansard]. Please explain, giving as much detail as you are able:

192. I have answered this above in response to questions 34 (c).

*(a) The extent of the Haemophilia Society's knowledge of this BPL products incident [**HSOC0002190**] may be of assistance);*

193. This letter from Lord Hunt, Health Secretary of the day, 31 January 2001 [**HSOC0002190**], shows the way in which the Society was involved, as the patient group, in communications and information to our members, alongside the UKHCDO and Department of Health. This was a very difficult ethical matter, given that there was no reliable test for vCJD or treatment for it if diagnosed, and given that the risks of transmission from a plasma donor could not be quantified at that time. As a patient organisation, we were reliant on other bodies to inform us about an incident of this kind, as we were not part of the NHS or any other statutory body.

(b) The extent of the Haemophilia Society's involvement, if any, in the BPL products incident;

194. As stated above, we were involved in consultation with the Department of Health and providing members with information/communication. I cannot recall the specifics.

(c) The Haemophilia Society's view on the Department of Health/National Blood Authority's advice with respect to patient notification following the BPL products incident;

195. The Society's view was that patients and their carers have a right to be informed.

(d) Whether the Haemophilia Society conveyed its view on patient notification in relation to the BPL products incident to any relevant entity, and if so, to whom, when and what was communicated. Please also set out what, if any, response was received;

196. I do not have detailed recollection of whether the Society conveyed its views on patient notification in relation to the BPL products incident to any relevant entity, to whom that would have been (if anyone), when and what was communicated (if anything) or what response was received (if any). However, as stated above, our view was that patients had a right to be informed.

(e) The extent of the Haemophilia Society's involvement, if any, in patient notification exercises relating to the BPL products incident;

197. The Society was involved informing and communicating with our members. This was through letters and via the Bulletin. As stated above, we were involved in coordinated action to inform patients with the UKHCDO and haemophilia centres. A number of communications to patients went out: from the Society to patients who were members on our database, and direct from the haemophilia doctors to their patients. We were involved in discussions as soon as the incident was notified to us with the UKHCDO and with haemophilia nurses.

198. There was a debate about whether or not patients would want to know if they had received the vCJD affected product or not. This difference existed both amongst patients themselves – some preferred not to know, others very much did want to know – and their clinicians, the haemophilia doctors. So, there were different options for the way the doctors would go about notifying patients. The Society's centre doctors questionnaire in December 2001 [**HSOC0004244**] was sent out to gather a national picture of how the doctors had informed their patients. So, it asked whether they had notified only those patients who had received the affected product or the whole patient group, and about how they had done this e.g. letter, phone call, personal consultation at the centre.

(f) Details with respect to any psychological counselling or financial support offered by the Haemophilia Society relating to the BPL products incident;

199. I do not have detailed recollection of the details with respect to any psychological counselling or financial support offered by the Society relating to the BPL products incident.

200. As mentioned above, calls to our Helpline showed us that patients and their families were very distressed and angry about the potential exposure to vCJD through a plasma donor. It was no consolation at all to be told that this risk was 'theoretical' by Government. There was a high profile in the media about vCJD, stories of people who had died from it and the symptoms, which were grim. It was, frankly, a terrifying disease for which no treatments existed. For this reason, there was a strong case for providing counselling support, and (as mentioned above) we had evidence in the form of the many calls to our Helpline. The evidence would be from the Society's staff who could convey the level of emotional distress in the calls they received – qualitative evidence – as well as in the quantifiable numbers of calls on vCJD. There was already awareness of the value of counselling for patients and their families, based on experience within the health service and voluntary sector of responding to HIV infection.

201. The centre doctors questionnaire in 2001 [**HSOC0004244**] asked about counselling support provided by the haemophilia centres, and this might have enabled us to form a view as to whether there was a need for additional counselling support. However, I do not have access of the results of that survey and what evidence it may have provided for a national counselling service. I do not recall that we had received funding to provide this counselling when I left the Society: only that we may have made a case for it based on the survey findings and calls to our own helpline. I do not recall offering any financial support to individual patients affected by the BPL recall.

(g) Whether the Haemophilia Society kept a record of any concerns and/or issues raised by haemophilia patients relating to the BPL products incident, and if so, whether this information was shared with any entities, such as the UKHCDO or the Department of Health. If it was shared, please set out with whom it was shared, what was said and when. Please also set out what, if any, response was received;

202. As the patient organisation, it was our role to provide views and feedback from our members on these issues to the UKHCDO and the Department of Health.

203. We would have received feedback directly from patients via our Helpline, and we would have recorded numbers of calls. I do not recall whether there was further analysis of the calls in terms of content, but I recall that some were distressed and angry. We would have passed on this overview, I believe, in speaking on behalf of patients to UKHCDO and Department of Health. I cannot recall any more detail than that. As the national patient group, we were invited to discussions with Department of Health and UKHCDO about how best to address this very difficult matter. We continued to state our view that patients

should not be exposed to the 'theoretical risks' of vCJD and that this would be avoided by treating everyone with recombinant.

204. As set out above in my evidence, our campaign for recombinant was active and high profile: our case for recombinant was strengthened by the BPL vCJD plasma donor incident. My article in the Bulletin Spring 2001 [**HSOC0023040**] states '*We will continue to put this view to the Government, and hope that local groups of the Society and individual members will campaign in their own area. Now is the time to step up the pressure on the Health Ministers Alan Milburn MP and Lord Hunt, who are still considering whether to take action'.*

*Question 36: The Inquiry is aware of questionnaires relating to the BPL products incident referred to at paragraph 35 that were sent to haemophilia centres, and which were returnable to you [**HSOC0004244**]. Please explain, giving as much detail as you are able:*

(a) What the Haemophilia Society did with these questionnaires following receipt;

205. As stated above, I do not have the results of the survey, and cannot recall what the Society did with those questionnaires following receipt though I believe our staff may have collated the results.

(b) What the purpose and objective of this exercise was;

206. As mentioned above I believe we sent the questionnaires to doctors at the centres to ask about counselling support provided by the haemophilia centres, as this might have enabled us to form a view as to whether there was a need for additional counselling support. This was for the purpose of learning and improvement i.e. to gain as accurate a picture as possible about how the centres had handled communication of the incident to their patients and to seek feedback on whether anything could be done better in future. I do not have access of the results of that survey but I believe it may have been the Society's intention to argue for a national counselling service.

(c) Whether the data from completed questionnaires was collated or input into any database, or recorded in any form, and if so, what (if any) findings were reached with respect to that data;

207. I believe that the results would have been analysed to provide an overview. However, please note that no patient information was being obtained in this survey. The survey was sent out to produce an overview of how the centres had handled the communication to

their patients. It was probably analysed in Excel to generate quantitative results, but I cannot recall specifically.

(d) Why the Haemophilia Society was tasked with receiving and/or processing the answers to the questionnaires.

208. I cannot recall why the Society was tasked with receiving and/or processing the answers to the questionnaires, but it may be because we had more staffing resources than the UKHCDO and therefore we were better placed to handle responses. The UKHCDO did not have an office, I believe, or any staff. It was probably more practical therefore for the questionnaires to be returned to the Society's office where we also had staff who could deal with them when they came back in.

Question 37: The Inquiry is aware of further patient notification exercises between 2003 and 2009, in particular the large-scale notification exercises commencing from 2004 notifying patients they were 'at risk' of vCJD. Please explain, giving as much detail as you are able:

(a) The Haemophilia Society's involvement, if any, in the notification exercises between 2003 and 2009;

209. This period largely falls outside my tenure as I left in 2004. At the point when I left the Society in April 2004, as far as I recall the most recent incident was the BPL affected plasma in 2000, referred to above.

210. In 2003, the Society was involved in discussions with the national CJD Incident Support Group as evidenced by minutes of the meeting on November 4, 2003 at the Health Protection Agency [**HCD00000829**]. The purpose was to discuss the development of support for patients and health practitioners in dealing with CJD incidents. From the minutes it appears that at that time there may have been two incidents involving vCJD affected plasma product from BPL. Dr Frank Hill, at that time the UKHCDO chair, talked about the collaboration with the Haemophilia Society to synchronise communications to patients. In the minutes, it records that I said that there was a need for a rapid response to incidents, and this might require more funding for extra staff for a limited period to address the need for support. I stated that it was difficult for a small voluntary organisation such as the Society to cover the demand for information and advice. There was discussion of the need for special training about vCJD for those involved in counselling patients about the risks of vCJD, and it is possible that this was provided for our own Helpline staff I cannot recall if this took place.

(b) Details of any psychological counselling or financial support offered by the Haemophilia Society following the notification exercises between 2003 and 2009:

211. This period largely falls outside my tenure and so I am unable to provide details of any psychological counselling or financial support offered by the Society following notification exercises between 2003 and 2009. As stated above, it is possible that some of our staff may have received training on vCJD to assist in handling calls, but I cannot recall.

9.2 The Department of Health study with UKHCDO

Question 38: The Inquiry is aware of the joint 5-year surveillance study between the Department of Health and the UKHCDO with respect to vCJD [HCDO0000266_081 & HCDO0000109_013]. Please explain, giving as much detail as you are able, what involvement, if any, did the Haemophilia Society have in respect to this study. What was the view of the Society about this study? Were those views communicated to the Department of Health and/or the UKHCDO? If so, please set out to whom they were communicated, what was said, when and what, if any, response was received.

212. I cannot recall in detail what took place at that time, only that the Society was involved in consultations with the Department of Health vCJD Incident Panel, and our role was to represent the patient group. There were very important research questions to answer about the possible risks that vCJD could be transmitted in blood or blood products, and we continued to voice the patients concerns about the possible risks. As stated in document **HCDO0000266_081**, there had been three recalls of BPL products since 1997 linked to a donor who had vCJD. The Society was supportive of research to monitor patients who might have been exposed through NHS treatment, for this reason, and this can be seen in the document written by me as CEO.

213. I am unable to advise in any more detail what involvement, if any, the Society had in respect to this study, or what the view of the Society was about this particular study; whether those views were communicated to the Department of Health and/or the UKHCDO, to whom they were communicated, what was said, when or what, if any, response was received.

9.3 vCJD National Surveillance Database

Question 39: The Inquiry is aware of the Haemophilia Society's consultation response on the establishment of a vCJD national surveillance database and its views on the proposal for a vCJD national surveillance database [BART0002012] and [NHBT0096710_001]. Giving as much detail as you are able, please answer the following:

(a) How did the Haemophilia Society gather views from its members? How many members contributed to this consultation response?

214. I do not have information on how the Society gathered views from its members or how many members contributed to this consultation response, and cannot answer from memory.

(b) Please expand on the views of the Haemophilia Society with respect to the creation of the vCJD national surveillance database. Specifically please give more detail as to what its views were in relation to the database and why the Society took that position.

215. As stated above, we were supportive of research to provide more information on the possible risks of vCJD transmission.

(c) The Society's document noted that the response relating to whether patient consent should be required was split Yes/No, with the ultimate view expressed that consent should be required for the establishment of a database. Are you able to further expand upon what other views were expressed on this issue by members? What was the split between Yes/No?

216. I cannot recall what other views were expressed on this issue by members or what the split was between Yes/No.

(d) What other steps, if any, did the Haemophilia Society take to convey its views on the vCJD national surveillance database, particularly patient consent, to any relevant entity, such as the UKHCDO or vCJD Incident Panel?

217. I cannot recall specifics of what other steps, if any, the Society took to convey its views on the vCJD national surveillance database, particularly patient consent, to any relevant entity, such as the UKHCDO or vCJD Incident Panel.

(e) Did the Haemophilia Society face any opposition to its views on the national surveillance database and if so, what were those opposing views?

218. I do not recall if the Society faced any opposition to its views on the national surveillance database and, if so, what those opposing views were.

(f) What was the nature and extent of the Haemophilia Society's involvement in the vCJD national surveillance database?

219. As the national patient group, we were consulted by the Department of Health.

(g) Did the Haemophilia Society's views with respect to the vCJD national surveillance database change over time?

220. I am not aware if the Society's views with respect to the vCJD national surveillance database changed over time.

9.4 Financial Assistance – vCJD

Question 40: The Inquiry is aware the Haemophilia Society had mentioned the need for more funding in the lead up to patient notification in the context of vCJD, such as additional staff at the Haemophilia Society "when crises arise" [HCDO0000829]. Please, giving as much detail as you are able in relation to:

(a) What the concerns of the Society were;

221. As stated above, we were aware from calls to our helpline of how difficult it was for patients and their carers to receive information about vCJD incidents. We were a small voluntary organisation, and we noticed a large increase in calls to the helpline due to the vCJD notification. This information was potentially quite traumatic to receive, as vCJD was an alarming disease, and there was no treatment or cure at the time. Even if Government stated that the risks of vCJD infection via blood products were 'theoretical' this was not reassuring for those who might have received affected products. Staff dealing with calls on such a difficult subject would need training and support.

(b) Whether funding was formally requested in that regard;

222. I do not recall whether funding was formally requested in that regard.

(c) If so, whether funding was granted to the Haemophilia Society, how much was granted and whether it was restricted funding;

223. I cannot recall whether funding was granted to the Society, or if it was, how much was granted and whether it was restricted funding.

Section 10: Relationship with Pharmaceutical Companies

10.1 Financial Relationships

224. In a specialist treatment area such as haemophilia, often referred to as a 'community', the role of pharmaceutical companies was important to the Society, as members of that patient community are reliant on the treatment products those companies provide in order to control their bleeding disorders and lead as normal a life as possible. Hence there is a rationale for a patient group such as the Society to maintain relationships with the pharmaceutical companies involved in this specialist treatment area.

225. By way of context for those relationships in the field of haemophilia and bleeding disorders, there is a shared and unique history between patients, the specialist medical teams and the pharmaceutical companies. The history of the evolution of modern treatment for haemophilia patients was reflected in the lifetime experiences of many of our members, including trustees on the board. Over their lives, being born with haemophilia had gone from a time when there was no treatment; bleeds were painful and potentially fatal, through the development of the first blood products to the arrival of recombinant, which enables the modern generations to lead normal lives. During the same era, the contaminated blood disaster, the impact of blood borne viruses HIV and hepatitis C and then vCJD, form part of that shared history. For that history not to be repeated, the Society campaigned for the safest treatment – at that time recombinant – for all patients and rightly expected that the companies producing treatment products would be held to the highest safety standards by the NHS and Department of Health, and the regulators. In this sense, the Society's relationships with the companies were important to our role as an advocate on behalf of our members for the safest possible treatment to be provided for all patients.

226. Equally important was and is the charity's independence. This is clearly stated in the principles set out in the charity's Rules and Guidelines for Working with Commercial Organisations (see **HSCOC0012920** as reference). As CEO, I was responsible for introducing those rules and guidelines, which were approved by the trustee board in May 1999, and continued to be applied thereafter.

227. Regarding, the financial relationships between the charity and the companies, these would have been covered by the charity's governance policies, specifically the Rules and Guidelines referred to above, and accounted for within the statutory report and accounts submitted to the regulator, the Charity Commission, under the standard charity accounting procedures of the time. An examination of the report and accounts during that period would indicate the proportion of income derived from pharmaceutical companies.

Question 41: 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. [HSOC0012920 may be of assistance].

228. Like other charities, the Society relied on a mix of income streams: membership, community fundraising, individual donations and legacies, grants from trusts and foundations, Government grants and corporate sponsorship. A board report by me dated 30 March 2004 **[HSOC0020091_012]** states that pharmaceutical company support averaged around £150k a year. For the financial year ending 31 December 2003, the statutory report and accounts show that £147k was received from corporate funding out of a total income of £763k. I cannot recall the specifics of each and every funding arrangement, but can refer the inquiry to the published report and accounts of the charity over my tenure for information. Those documents should be held by the Society. As a general overview, the funding from companies tended to be used for specific purposes such as the costs of an event or a publication, rather than as general core funding.

Question 42: Was the Society's relationship with BPL different to its relationship with the pharmaceutical companies? If so, please explain how.

229. The relationship with BPL was different as it was a different type of organisation, being part of the NHS, from the commercial pharmaceutical companies, I believe. It was, to my recollection, related to or part of the National Blood Service, and had been a regular funder of the Society historically. Detail of the level of funding is recorded in Trustee Board minutes and Statutory Report and Accounts over the period of my tenure. Those documents should be held by the Society.

Question 43: 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.

230. As a charity, the Society raised income from various sources, of which pharmaceutical companies were one, as noted above. Relationships with funders would have been managed through our fundraising staff, as they were responsible raising income for the charity. As CEO I would have had some involvement, as would trustees, in relationships with individual companies. I cannot recall specific relationships in detail.

231. Income was declared as noted above in statutory report and accounts, and funders were identified in communications by the Society. Examples of this can be seen in member communications, e.g. sponsorship received for a specific members event would be listed by company names.

232. Methods of communication would have been by meetings, and by letters or emails. A fundraising database (Raisers Edge) was maintained by the fundraising staff to record donations received.

Question 44: 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?

233. During my time, we employed two professional fundraisers whose role was to bring in the income to sustain the charity. As CEO, one of my responsibilities was for finance and fundraising strategy, and this was in the context of potential and actual loss of income from statutory sources and the need to launch a new fundraising strategy in 1999 to ensure the financial sustainability of the charity. For further evidence on this the minutes of trustee board meetings during this time and of the Resources Committee would be relevant and should be held by the Society. Factors that would influence the level of funding from companies would be mainly to do with their own budgets and priorities, which would influence their decisions about whether to fund and how much.

Question 45: 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?

234. Individual pharmaceutical companies would have had different areas of interest, dependent on the type of treatment products/field they were involved in. Donations would have varied in size, this might be dependent on the amount of budget available within different companies for charitable support/donations. Generally, the companies wanted to sponsor specific projects e.g. an event or conference for our members. To my recollection, they were not 'core funders' of the charity, and all contributions were used to support activities as far as I recall. Names of supporting companies were listed in information/communications and in the statutory report and accounts for transparency. Those documents may be held by the Society.

Question 46: 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?

235. I cannot answer on behalf of the pharmaceutical companies as to their motivation in providing donations in support of some of the Society's activities. Their motivation may

have been partly philanthropic, and partly an aspect of their marketing/PR through which they would seek to build the profile of their company and brand. It would be standard practice for most funders to seek an acknowledgement of their funding and logos were included on publications that were sponsored.

236. However, I can state that the Society was very clear about our independence as a charity and that funding agreements with companies were governed by our Commercial Sponsorship Guidelines. Generally companies wished to sponsor a specific piece of work, such as an event or a publication. See reference to the Commercial Sponsorship Guidelines of the Society in place during my tenure [**HSCOC0012920**].

Question 47: A number of the Haemophilia Society Bulletins record which pharmaceutical company funded the production of the Bulletin. Was that record a requirement of their funding? What was agreed in this regard? How was this agreed?

237. As a charity, there was a requirement for us to be transparent about funding received, and this was done in two main ways: in our statutory report and accounts and in stating the names of commercial funders clearly in any publications. Equally, the companies themselves might wish (as funders generally do, not only commercial ones) to receive some recognition of their contribution. It would be standard practice for most funders to seek an acknowledgement of their funding. With regard to agreements, the fundraising staff would be directly involved in recording funding received, and in any sponsorship agreements.

238. For transparency, the Society declared the funding support we received from companies, and hence this can be seen in the Bulletin. As stated above, our funding relationships with the companies were governed by the Commercial Sponsorship Guidelines: [**HSCOC0012920**].

Question 48: 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.

239. It was not the Society's role to promote the products or image of the companies and the Society did not actively do so, other than through logos being included on publications that were sponsored. I cannot name the companies from memory, but I do know that they were listed so that this information was transparent. The companies had their own marketing

budgets to do this. As a charity, the Society's role was to deliver our charitable mission and this did not include promotion of companies.

Question 49: 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.

240. To my recollection, the Society during my tenure did not do so. Our funding relationships were conducted under the Guidelines already cited.

Question 50: 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.

241. I am not aware of the Society refraining from publishing or disseminating any articles or publication in exchange or with the expectation of receiving financial contributions or any other benefits from pharmaceutical companies.

10.2 Other Relationships

Question 51: 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.

242. I cannot recall the Society relying on pharmaceutical companies for assistance or support, other than financial contributions.

Section 11: Other Issues

Question 52: 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?

243. To the best of my knowledge, during my tenure 1998 to 2004, no staff or committee members purposely or intentionally destroyed documents relevant to the Inquiry's terms of reference.

Question 53: Please explain, in as much detail as you are able to, any other matters that you believe may be of relevance to the Infected Blood Inquiry, having regard to its Terms of Reference and to the current List of Issues.

244. I have nothing further to add.

Statement of Truth

I belie[redacted]rue.

Signe[redacted] GRO-C

Dated 14 May 2021