Witness Name: Liz Rizzuto

Statement No: WITN5684001

Exhibits: WITN5684002 - WITN5684007

Dated: 30 July 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LIZ RIZZUTO

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 May 2021.

At the outset, I want to say that I hold very limited documentation, both in paper form or electronically regarding the matters covered by the Rule 9 request. This statement is, therefore based on my recollection, supported by Rule 9 documentation and the documents the Inquiry has referred to me, but without access to a wider body of documentation.

I, Liz Rizzuto, will say as follows:

Section 1: Introduction

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

1. My name is Elizabeth (Liz) Rizzuto. I reside at GRO-C, GRO-C. My date of birth is GRO-C 1960.

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

2. I am currently employed in a part-time capacity by Northamptonshire Police as ANPR Auditor. Prior to this I was employed by the Stroke Association. I was employed by them as a facilities manager from August 2014 until April 2021, when I took redundancy. My previous employments is as follows:

   Dec 2013 to Aug 2014: Northants County Council – Executive Assistant to the Head of Looked After Children. Temporary Position.

Sep 2012 to Nov 2013: City of London Police – Office Manager Professional Standards Department. Temporary Position.

1999 to 2011: Northants Police & Association of Chief Police Officers. HR Administration Manager / Office Manager PREVENT Delivery Unit. I held these full time roles whilst executing my role as Trustee/Chair of the Haemophilia Society.

Before having my children in 1987 and 1990 I worked in various roles within the private and public sectors.

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

3. I have been and continue to be a member of the Haemophilia Society (HS) GRO-A GRO-A GRO-A. Myself GRO-A are both carriers. I have also been a member of two local groups Lincolnshire & Northamptonshire. Looking back at some of the disclosed documents, I am reminded that I was active on some sub-groups i.e. parents and young families & women and bleeding disorders. In June 2004 I became a Trustee of the Haemophilia Society and was appointed Chair in the October or the November of 2007, when Roddy Morrison stood down. I finished my term of office in November 2011 at the AGM in Glasgow and handed over to Bernard Manson.

4. From November 2007 I took over from Roddy Morison as Chair of the Haemophilia Society, and also acted as co-chair of the Haemophilia Alliance with Dr Jonathan Wilde (Queen Elizabeth Hospital Birmingham & the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO)). Jonathan usually chaired the meetings. I cannot recall if I chaired any during the time I was involved. The Haemophilia Society also made up the membership of the Alliance with staff and representative members of the Society. The Alliance Meetings were held at Department of Health (DoH) at Wellington House. I think these were held twice a year.

5. In 2011/12 I also supported the Macfarlane Trust/ Caxton Foundation with some recruitment. Specifically for the Chair and Trustee positions for the Caxton Foundation – please see paragraphs 99 – 102 in my statement for further detail.

6. Since January 2019 I have been a Trustee of Haemnet a charity which supports the education and research for health and social care professionals working with people with bleeding disorders.

Section 2: Previous Evidence

Q4: Please confirm whether you have provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. 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 been involved personally with any other inquiries or litigation in relation to the infections listed. I was notified some years ago that GRO-A GRO-A GRO-A but I have not instigated or been involved in any litigation in respect of vCJD.

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

Q5: Please confirm and outline your role and the responsibilities within the Society, including responsibilities held in relation to other groups and organisations. If these changed over time, please detail when and why.

8. As outlined above. I have been a member of the HS since 1991 GRO-A GRO-A. I became a Trustee in 2004 and chair in 2007 of HS. Following the departure of Margaret Unwin as CEO in 2006, I assisted with the recruitment and selection process for the new CEO and along with another Trustee Anne Hithersay, I interviewed Chris James as Margaret's replacement. The paper sift and shortlisting of applications was completed prior to interview by my predecessor, Roddy Morrison, myself and three other Trustees (Debra Pollard, Dawn Prideaux de Lacey, Gareth Lewis). My role was non-operational in as much as the day to day running of the office and delivery of objectives was down to the CEO and the staff team. We conducted a review of staff salaries in 2007 and some paperwork I have shows the staff team was in the region of about 9 members of staff, including the CEO. I am unable to recollect what the staff establishment was by the time I stood down in 2011.

9. My voluntary role as Chair was to support the CEO, particularly with staffing issues, to act as the conduit between the Board, the membership and the CEO, and to ensure the Board meetings were held appropriately and consensus was reached amicably.

The role of the Board was to ensure the CEO and staff team executed their roles and the various work streams in order to deliver the aims and objectives of the Charity with due diligence and appropriate financial governance.

10. The majority of my time outside of board meetings was spent discussing or dealing with ‘HR’/personality issues amongst staff and Trustees. As I was working full time for the police service in a sensitive role and commuting to London from Northampton daily. I was perhaps not as involved operationally as some of the former or subsequent Chairs who did not have full time employment but I remained committed despite my work commitments. Apart from my role as Chair, the board consisted of one if not two Vice-Chairs and a treasurer and trustees who either had a bleeding disorder or was a parent or relative of a person with a bleeding disorder. To the best of my knowledge, the Board had for a number of years had a Haemophilia Nurse on the Board and I believe still does. The structure of the Charity, a CEO, staff and a quorate number of trustees has been standard for years. To the best of my knowledge, the number of paid staff, the issues of the day, the management style and board of trustees and obviously personalities have changed and varied over the years the Society has been existence.

11. I also was Co-Chair of the Haemophilia Alliance and I helped select Haemophilia Society membership representation on the McFarlane Trust (MFT) Board. As Chair I fronted the AGMs and attended European Haemophilia Consortium (EHC) and World Federation of Hemophilia (WFH) events along with the CEO. As a collective, the Board would meet with the CEO and agree budgets and programme of events, activities and fundraising initiatives

Q6: 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.

12. The objectives of the Society have always been to provide advocacy, information and support to people with inherited bleeding disorders (Haemophilia / von-Willebrands) and their families/carers. This has been done by providing (not entirely or exhaustively); literature, family days / weekends/ conferences, helplines, local groups. Work also included advocating for fair treatment and support for people with inherited bleeding disorders. The Charitable Objects states: The relief of people suffering from haemophilia and related or associated bleeding disorders and the advancement of public education into the nature and causes of Haemophilia and related or associated bleeding disorders.

Q7: 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.

13. The Society was structured like most charities; the CEO was responsible to the Board of Trustees and responsible for the staff team and day to day running of the Society. Individuals took responsibility for their areas of expertise – fundraising/support/advocacy/HepC support worker etc. There was also an office manager/finance officer/receptionist/ administrator. I think the staffing structure did alter during my time and this may have been due to funding streams / loss of government grants and by natural wastage (resignations). I am sure restructure and redundancy did happen but I cannot recall specific details. The structure and governance remained the same although there would have been a change in some of the Board members when their term of office was up. This would usually happen at the AGM. Chris James set out our Vision in Issue 1 of HQ in Spring 2008 where it states that our strategic aims and objectives reflected what the membership was seeking. It also mentions a needs assessment that was carried out in 2007 of which I have no recollection. The Vison, Values and Aims would have been signed off by the Trustee Board. These were **Vison:** Freedom to make choices and seize opportunities for people affected by bleeding disorders. **Values**: to be motivated by the needs of the people affected by bleeding disorders; to act with integrity, honesty and transparency; to deliver the best use of all our resources; to be inclusive; to maintain our independence**. Overall aim**; To ensure that people affected by bleeding disorders have the freedom to make choices and seize opportunities. The mission statement may well have changed since my tenure by successive Boards.

14. In 2008 we were looking to save £200K+ per annum and I think this was due to loss of funding from the Government and other income streams. We also had some volunteers to help support some of the HS activities. We would have around 4 to 6 Board meetings per year, a strategic planning day probably once a year with the Board to agree budget and plans. The CEO and staff, referred to as Subject Matter Experts (SMEs), for example a fundraising manager would present on their work and or their proposals at the Board Meetings and the Board would approve or ask for more information or on occasion not approve proposals.

15. During my term we did amend the Memorandum and Articles of Association to restrict the terms of office of Trustees, which meant that a Trustee could only serve a maximum number of terms that would mean they would retire entirely after 6 years continuous service. The Chair would serve for a three year term. This was done to

encourage new membership of the Board and discourage the same Trustees returning year after year. We wanted to encourage a more diverse representation on the Board. For many years there were the same people standing and we wanted to attract people from the membership with different skill sets to help support the CEO and staff team and to ensure the Board functioned effectively from a business perspective. So we needed financial acumen for the treasurer for example and the same for anyone with HR, or IT backgrounds for example.

16. We allowed for a Chair to be appointed who was not necessarily aligned to Haemophilia but had a background with more business acumen in order to support the CEO with an ever decreasing budget/staff establishment and competing priorities. I think this was in 2008, however this would be reflected in the relevant annual report and the Society's memorandum and articles.

Q8: Please describe the relationship between the Board of Trustees and the day-to-day management of the Society.

17. The day to day management of the HS was down to the CEO; the Chair would support the CEO and other Trustees would provide support to the SMEs i.e. the treasurer would support the finance officer, another would support the work of the information support officer. We ensured or tried to ensure we had representation on the Board from the other nations before Haemophilia Wales & Scotland were set up.

18. My recollection is the relationship between the Board and the CEO and staff was healthy. I have no recollection of any issues of competencies that gave cause for concern. Apart from myself and the CEO the only other dealings with staff by members of the Board that I can recall, would have been with the finance officer and treasurer, Dawn Prideaux de Lacy and Debra Pollard with the information and support worker. This would have been to do with the financial reporting and supporting any specific projects. Other than that I can only recall asking other Trustees to work on a review of the office rent and to deal with any HR issues that I and possibly the vice chair would need to get involved in as final arbiters. The Board would have had open and transparent discussions at meetings but I cannot recall any relationship issues that would be cause for concern. I considered my working relationship with the CEO was good and I didn't feel the need to micro manage. We would have also had a remuneration committee – we did a job evaluation exercise to ensure staff were paid appropriately.

Q9: What methods, if any, did you use to report the Haemophilia Society's activities to the Board of Trustees?

19. This question is more relevant to the CEO or staff member involved in such activities. The Board met regularly though and so were kept updated. In the event of anything unusual between Board meetings the CEO and or I would email the Trustees to let the Board know but mainly the Board were updated at the Board meetings. I set out my relationship with the CEO in response to question 14 below.

Q10: Please list all the different committees and advisory bodies that you recall were set up within the Society and describe the purpose, functions and responsibilities of each committee or advisory body.

20. I am unable to recall membership of committees but we had a Women and Bleeding Disorders committee, Inhibitor group, medical advisory board – to help inform the literature we produced. We set up a patient representative audit group before it became more formal in recent years with the CQC. There was a campaign group set up for Archer – this was set up as a collaboration group with other groups, however I am unable to recall any further detail. Mainly this was fronted by Dan Farthing (Policy & Communications) and the CEO, Chris James who I would expect would be able to provide the further detail. There were issues because of disagreements with the different factions and this put even more pressures on the CEO. I cannot recollect specific details and I did not attend all of the meetings. The HS was trying to facilitate and fund meeting venues for the groups to campaign. The HS tried to build cohesive relationships with campaigners whilst delivering its other services to the membership. Dan and Chris would have had the main dealings with the campaigners. I append a copy of the letter I sent to Manor House Committee at **Exhibit WITN5684002.** Although the copy of the letter is undated I believe it was sent in 2010.

21. I also recall the following groups, independent of the HS and set up by various campaigners. Unfortunately, I am unable to expand on their specific remits; however, Chris James and Dan Farthing would likely have further detail and those who headed up these committees/ groups.

- Tainted Blood Committee
- Haemophilia Action UK
- Contaminated Blood Campaign Coalition
- Campaign Group Members

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

22. Annual reports during my tenure may list task groups and membership. I cannot recall in detail but I was most probably involved in the Women and Bleeding Disorders and Inhibitors committee groups. Both of these would have had been made up of representatives from the membership, staff and appropriate medical practitioners (consultants or nurses or both). The groups would help inform what literature or help /advise/awareness we could produce. i.e media content in womens magazines, or what workshops we could run at weekends or AGMs. Inhibitors in Haemophilia is thankfully rare but there was little support or information for parents GRO-A GRO-A It is a frightening prospect so providing support and networking activities was something that was welcomed by those impacted by inhibitors. The purpose was to raise awareness and provide support. Before I was on the Board I participated in a small group for GRO-A which is referred to later in my statement about Hep C. Until I was referred to this I had forgotten about this small group.

Q12: In relation to the committees and advisory bodies that you have addressed above, please detail your role and/or involvement with them.

23. I helped establish working groups and held workshops/presentations at AGMs. My involvement would either be to help facilitate the groups' activities / discussions and suggest suitable membership. These were informal gatherings that helped in providing information or support networks and helped members share their experiences. For example, many women, including some in their 70s wanted to share their experiences and they were grateful to find out that they were not alone or unique. None of these groups were campaigning groups. I was involved because both of this subjects – women and bleeding and inhibitors were personal to my own experiences. In short I was a participant.

Q13: Please identify which of these committees and/or advisory bodies, if any, provided medical advice and/or opinions on the safety of blood products and/or the risks of transmission of diseases, including vCJD, to the Haemophilia Society's Trustees and staff. With regard to these committees, please answer the following:

24. None of the committees mentioned above provided advice or opinions on transmission or safety of blood products. It wasn't relevant to the topics we discussed. We would have discussed treatment options for heavy menstruation (Mirina coil) or the pros and cons of having a port-a-cath for delivering immune tolerance therapy for inhibitors.

a. ***Did any clinicians attend any of these committees? If so, please set out how they were selected to join the committee(s).***

25. Yes, we would have had clinical nurse specialists or clinicians/gynaecologists who treated women with bleeding disorders. I think we would have discussed at Board level who might be willing to help or support and we would have asked them if they would like to contribute. Debra Pollard was Clinical Nurse Specialist at the Royal Free and we all knew of relevant others who we might suggest. I cannot recall who would have approached them but most likely Debra or the CEO.

b. ***Did any representatives of pharmaceutical organisations attend any of these committees? If so, please set out how they were selected to join the committee(s) and what their role on the committee(s) was.***

26. Not that I can recall. It was irrelevant to the groups I have mentioned above.

c. ***To what extent, if at all, did the Haemophilia Society rely on findings or conclusions from these Committees to form its policies?***

27. The findings and outcomes would have helped inform our publications, services and support. In the main I saw the Women and Bleeding as a support group /network.

d. ***To what extent did the Haemophilia Society verify the accuracy of reports and discussion documents produced by these Committees? If so, please provide details.***

28. I am not sure that reports and discussion documents is the right terminology in respect of these support groups. The work that came out of them be it publications, articles, workshops at meetings were all informed by the personal experiences of those taking part. We would have been confident in the input from the professionals involved. i.e Debra Pollard or her peers.

e. ***To what extent did the Haemophilia Society rely on its own judgement when deciding whether or not to formulate policy on the basis of the findings or conclusions from these Committees?***

29. In the examples of the groups I have highlighted we would have formed our own judgment based on the discussions and outcomes. For example, women and bleeding disorders resulted in Woman Bleed Too and as far as I am aware the Haemophilia Society still produces work on this subject. I do not believe we would have given specific advice or bias to treatments or products.

f. ***Please give all examples, relevant to the Inquiry's Terms of Reference, of when the Society did not follow the advice from these Committees.***

30. I am not aware of examples of where we didn't follow 'advice'. I am not sure the question fits the topic in the scenarios above.

31. **vCJD:** By the time I was a Trustee the risks of transmission of HIV and HepC were already known. vCJD became an issue during my tenure (I was informed GRO-A GRO-A around the time I became a Trustee (July 2004)). I append a letter and fact sheet that was sent to me GRO-A about vCJD dated September 2004 **(Exhibit WITN5684003)**, though I am unable to recall what information was sent out to the wider membership of the Society. I cannot recall if we had a separate working or advisory group looking at vCJD but I seem to recall that we had an expert from Scotland (James Ironside) who may have helped in drafting any information we may have sent out.

Q14: Please explain your working relationship with the Chief Executive Officer in your role in the Haemophilia Society. What was their role in relation to yours? How closely did you work together on decisions?

32. In my role as Chair of HS, I was, in effect the CEO's line manager. Mine like all the Trustees was a voluntary role and unpaid. The CEO and staff were salaried. We had a good working relationship, I supported him particularly with staffing issues/disciplinary issues etc. In respect of the day to day operations I was happy for him to have autonomy to manage himself and the staff team. His role was to manage the staff team, and deliver whatever objectives and strategy he and the Board would have agreed. Any other decisions in respect of the direction of travel for the HS, budgets etc was taken collectively with the Board. We didn't work together per se, he was entrusted to get the job done and arrange meetings with whomever was necessary i.e. Pharmas in respect of projects that we wanted to deliver, attend APPG meetings or meet with Lord Morris our President and who was already trying to drive through Archer (pre my term of office). Any discretion may have been a given in respect of staff issues. I would not say that the CEO carried out any meetings or work streams without the support or knowledge of myself or the Board. I cannot recall a time where the CEO or I made any critical decisions without the rest of the Board's knowledge. We may have deferred to the officers (Treasurer /Vice Chair) only, on some occasions but I cannot be specific. The Board acted as collective decision makers by reaching a consensus or majority decision.

Section 4: Communication and Dissemination of Information by the Society

4.1 Publications

Q15: Please identify the members of the Board of Trustees and/or committees of the Haemophilia Society responsible for editing and selecting material for the Haemophilia Quarterly ("HQ") and other Haemophilia Society publications during your tenure.

33. Unfortunately I am unable to fully recall if Trustees would have routinely contributed to the HQ. I think there was a standing running order that included the CEO's report and covered the key areas of operational business, fundraising, events, policy and communications. I recall that most additions of the HQ would have covered the same topics unless there was something exceptional to report on for example, Archer or updates on products or campaigning. Dan Farthing Communications Manager and Chris James as CEO during my tenure used to have responsibility for pulling together the content of HQ and I think myself and vice-chair Debra Pollard may have proof read any content before final print. Any information publications/leaflets produced by the Society would usually reference authors or reference articles/contributors. I assume they still do. As previously mentioned, we would ask experts to contribute. The Inquiry would need to review any available publications. However, I have shared a fact sheet that was issued on vCJD which lists contributors on the back page, if this is helpful **(Exhibit WITN5684003)**.

Q16: 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?

34. We will have included some articles where Pharmaceutical companies may have produced some text (mainly if they were funding certain projects or awards). However they would not have had any editorial rights or other input in material included in the publications of HS, to the best of my knowledge. They may have funded the production of leaflets and may have provided some data but they would not have necessarily had full editorial rights. The Pharmas did produce their own literature for example Baxter produced a travel guide which was helpful as it had all the addresses of the Haemophilia Centres in the world. I do not believe there was any bias towards one Pharma over another and do not believe they influenced what we produced. As above, Dan Farthing and Chris James may be able to provide more insight on this point.

Q17: How did the Haemophilia Society select or identify contributors and interview subjects for its publications? What were the criteria, if any, for someone to be able to write an article for a publication?

35. As above, I think there was a standard running order ie. usual contents generally covered, for example operational business, fundraising, events, policy and communications but anything else that was relevant would have been included. We were keen to have input from the Society's membership and we may have asked for members to write articles. Trustees would have also been asked to report back on conference attendance and learning/ information relevant to provide to the wider Society membership i.e from WFH meetings. Dan Farthing would be better placed to provide further detail on this.

Q18: Specifically, in relation to its publications which gave medical and/or other similar opinions including those on treatment options:

a. How were the contributors identified?

36. If my memory serves me, the HS (CEO or staff member – depending on publication) or possibly a specific Trustee, probably Debra Pollard; would approach a known person. Haemophilia is a relatively small tight knit community and there were individuals who were well known of publishing papers in Haemophilia publications. I cannot specifically say who but examples might be Paul Giangrande from Oxford, Ted Tuddenham (Centre Director of the Royal Free and expert in gene therapy) or Charlie Hay from Manchester or other Centre Directors. Nurse input would have been garnered in much the same way.

37. The Trustees would all have relationships with their nurses or consultants, so we would all also be able to offer names of people who might be willing to contribute. So no one specific held the relationships.

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

38. The HS would have relied on medical professionals or their publications to help produce this advice. They were considered experts in their field. Staff and Trustees generally did not have the medical knowledge. For example, Ted may have produced or given a talk on gene therapy at an AGM which would have been relied on due to his expertise in this field.

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

39. This information should be obtained from the publications available from the HS as we usually would reference these individuals. As stated above I can only proffer some examples. I am unable to recall all of the publications during my tenure.

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

40. This has been addressed in a) above. It would depend on the subject matter and who was willing and in a position to contribute. We may have had a discussion at Board level or the relevant staff member or CEO may approach a known contributor.

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

41. I don't think it was anyone specific, again it would depend on the topic. It would be either the CEO, Communications officer/manager or possibly a Trustee, depending on the article.

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

42. The only example I have available to me is as per the factsheet produced on vCJD in September 2004 **(Exhibit WITN5684003).** The Inquiry would need to look at all available publications.

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

43. I am unable to answer this question fully. It may have been edited to make easier reading for the layperson (parent for example) to understand certain medical phrases, but I cannot say I can think of a specific answer.

Q19: In his evidence to the Penrose Inquiry, Chris James, Chief Executive of the Haemophilia Society, stated that, "the activities of the Society in disseminating information to its members were often spearheaded by haemophilia doctors" [PRSE0000851, page 3]. Do you agree with this statement? If so, please provide details identifying doctors where possible and detailing their activities in disseminating information to the Society's members.

44. Yes I would agree with this statement. During my membership (almost 30 years) and my tenure as a Trustee (7 years), the Society would hold events, including AGMs, family days etc and would usually include plenary sessions or workshops presented by members of the UKHCDO and Haemophilia Nurses' Association (HNA). The Inquiry

should be able to identify contributors from the publications and records of the AGM and minutes as they would be identified within them. I unfortunately cannot remember what was on the agenda at every AGM/conference/weekend or away day. We would have also published articles in the HQ and the Bulletin and it is likely they may have contributed if we had asked. Again, it would need to be verified by looking at past publications.

4.2 Communication with members

Q20: How did you interact with members during your tenure? What were the main concerns and issues reported or relayed to the Haemophilia Society? How did you respond to the concerns?

45. My interactions with members were limited during my tenure given my role within HS. I was in a voluntary role and therefore only met face to face with some of the membership at conference and events. I was contactable via the Society and local groups but to the best of my recollection I did not directly receive any concerns from the membership. The membership has always used the CEO as the conduit to queries and reporting of concerns. The CEO and I may have written joint letters on occasions but I cannot recall any particular instance as I write this statement. The CEO would be better placed to answer what concerns were raised.

46. At this juncture I cannot recall any specific concerns or issues relayed to the Society or to myself. Individuals may have raised issues specific to themselves regarding benefits possibly and if this were the case the staff member responsible would respond. Members would telephone in to the office to have their queries answered or by email or post. The only other example I can think of that may have affected some of the membership was the issue of vCJD which I have evidenced in the fact sheet and letter issued in 2004 **(Exhibit WITN5684003)**.

Q21: Did the Haemophilia Society receive direct inquiries from the public or members who required advice with regard to treatment with blood products, such as receiving recombinant 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 in order to respond to these queries and from whom that had been provided.

47. The CEO would be best placed to answer this in more detail. There would however have been publications available which included information for members or the public who had queries. Literature would have been produced in-house i.e a

haemophilia publication written by medical professionals and or literature produced by the pharmaceutical companies if it was a product specific to them. The support officer at the time would have possibly dealt with queries but I cannot be sure.

Q22: 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.

48. As mentioned previously we would have held various 1 day or weekend events and workshops for members that would have been chaired by SMEs i.e HNA for parents of newly diagnosed children. Dissemination of information would have been via the Society's web-site, mail outs to the membership, information stands at our AGMs/ away days. I think if anyone contacted the Society as a new member they would have been sent a list of available publications and probably an introduction to Haemophilia. When I joined as a member in 1991 I received Peter Jones' book 'Learning to Live with Haemophilia'.

4.3 Haemophilia Alliance

Q23: The Haemophilia Alliance had meetings twice a year with the Department of Health, as referred to in HSOC0023061. What were the goals of the Haemophilia Alliance? Who was in the Haemophilia Alliance and who from the Haemophilia Alliance attended these meetings?

49. The aim of the Haemophilia Alliance was to help inform and develop service specifications for people with inherited bleeding disorders, **and** to address issues such as the Service Specification and DashBoard for bleeding disorder services, applications to the Skipton Fund, eligibility for payments from the Caxton Foundation amongst many others.

50. I do not recall the exact contents /agendas of these meetings but the primary aim was to help inform the national service specification for Haemophilia care. See **Exhibit WITN5684004** is a letter dated 9 March 2012 from Chris James, CEO to Rowena Jecock, the Head of Blood Policy Unit of the DOH which set out the suggested approach to deal with issues raised**.** The list of issues as referred to in this letter and raised ahead of the Haemophilia Alliance Meeting on 28 May 2012 can be seen in **Exhibit WITN5684005.**

51. The membership was made up of individuals from multiple disciplines (which included UKHCDO, HNA, Social Workers, patient representative and members of the Blood Policy Unit). The membership of this meeting was quite large and included DoH Blood

Policy representatives and clinical and medical representatives from various bodies connected to the care and treatment of people with bleeding disorders. I cannot recall who attended the meetings other than myself, Chris James, Dan Farthing, Mark Ward from the Haemophilia Society. The UKHCDO will have had representation. Ben Cole from the Blood Policy Unit (DoH) should be able to assist regarding a list of attendees. These would have changed over the years the alliance was in operation.

Q24: Who did the Haemophilia Alliance meet with at the Department of Health? What format did these meetings take?

52. Usually the Haemophilia Alliance met with the Department of Health twice a year – see the list of membership as set out in the UKHCDO's Annual Report 2011. Membership was something in the region of 32 individuals representing the various groups and societies. In terms of who attended from DoH, I can only recall Ben Cole (part of the administration team in the Blood Policy Unit) and I think Rowena Jecock, Head of Blood Policy at the time. As above, Ben Cole would have held the attendee list.

Q25: During your tenure, what items were discussed at these meetings? How were topics decided upon to raise at these meetings? How much did the Haemophilia Society contribute to the list of issues which were sent to the Department of Health? How many of the issues were those raised by members of the Haemophilia Society?

53. As above, various issues were discussed like the service specification, access to treatments and Skipton funds. I cannot recall specifics but I do have a copy of the topics the Society wanted to discuss in May 2012 (see **Exhibit WITN5684005**). I cannot recall this particular meeting as I was no longer Chair but I did receive emails about the meeting. The CEO at the time will probably recall more information regarding these meetings as he always had the opportunity to contribute to the agenda and the meetings. As you will note from **Exhibit WITN5684004,** it was proposed that this list of issues would be worked through and issues that had been resolved be removed and new issues be added to the list. Reviewing this list, my assumption would be that some of these may have been raised directly by a member or members of the Society, through the Society or maybe through other channels, though I am unable to comment with any certainty.

Q26: How did the Department of Health respond to the issues which were raised? Were any assurances made? If so, how was it ensured that these assurances were actioned?

54. Rowena Jecock of DoH always responded well and was in my opinion open and honest in discussions with the Haemophilia Alliance. I cannot however recall any particular instances in respect of assurances made and actions taken.

Q27: Were minutes of these meetings recorded? If minutes were recorded, were they an accurate reflection of the meeting? Who was responsible for drawing up the minutes?

55. The CEO of HS would take notes and Ben Cole (of the Blood Policy Unit, DoH) would usually produce minutes that the CEO, the co-chair and I would approve. As UKHCDO representative, I expect the minutes would also have been sent to Jonathan Wilde.

Q28: Please also provide detail on the experts who attended these meetings or who were involved in these meetings. How did they assist in these meetings? Who were they, and who were they selected by? You may wish to refer to DHNI0000389 to assist you.

56. Please see **Exhibit WITN5684006**. All representatives were there to ensure their subject matter was on the table to the best of my knowledge. Selection was put forward by the interested bodies i.e UKHCDO, HNA or HS for example. HS sought interests from the membership. I am not in a position to provide detail about membership at the meeting document DHN1000389 refers to. The membership of the Alliance changed over the years. For example I replaced the previous Chair of the HS and Bernard Manson replaced me as Chair. I think the issues also changed after the Archer Inquiry and the recommendations that were made. I am unfortunately unable to provide any detail as to experts who attended these meetings. As above stated, I can only recall that UKHCDO representatives, HNA representatives and other DoH representatives attended. Ben Cole would be able to provide a full list of attendees.

Q29: Did you consider the Haemophilia Alliance to be efficient in its aims? Please provide as much detail as possible.

57. I am unable to recall specific goals of the Alliance after this length of time but I think the meetings drove service specification forward and I think we felt we had a seat at the table at least. As set out, I only had a short tenure on the Alliance, I think about three to four years. I am unable to recall the number of meetings during this time. I do not recall my tenure ending formally as I think Bernard Manson, my successor took over.

Section 5: Relationship with the Government

Q30: 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?

58. The CEOs and the communications manager had the main contact with any of the Government bodies on a day to day basis. To the best of my recollection the main meetings were with the APPG, and Lord Alf Morris, President of the Haemophilia Society. Lord Morris had been instrumental in setting up the Archer Inquiry. Routine correspondence would have been written to leaders of the parties and the Prime Minister's office. I personally cannot answer who the main points of contact were or how the relationships were formed. The only regular meeting I can say I attended would have been the Alliance meetings at the Department of Health. I would suggest the CEO would be better placed to answer this question.

Q31: Please describe the extent of your role and involvement with regard to the Society's interactions with and representations to the Government.

59. I personally had very little involvement with Government representatives as I was in full-time employment. My name may have been added to letters that were sent out by the Society. I met with Lord Alf Morris, President of the Haemophilia Society, with the CEO and had telephone conversations with him on occasions. Apart from Alliance meetings where DoH Blood Policy Unit were in attendance, I cannot recall any other dealings that I personally had on behalf of the Haemophilia Society with Government representatives.

Q32: If you attended any meetings, please provide a detailed account of those meetings with Government ministers and/or civil servants and/or other representatives of the Government. In particular please set out the following:

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

60. I do not recall attending any meetings other than the Alliance Meetings at the DoH.

b. Who did you meet with?

61. As above, I am unable to answer this question.

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

62. The Alliance meetings were recorded by Ben Cole of the DoH's Blood Policy Unit

d. What were the purposes of the meetings?

63. As above, I do not recall attending any meeting other than the Alliance Meetings at the DoH

e. ***What was discussed at the meetings?***

64. I do not recall attending any meeting other than the Alliance Meetings at the DoH

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

65. I am unable to recall any responses to the Society's position. Any responses pertinent to issues at the time of my tenure would be in the Society's archives I would hope. I cannot recall anything specific during my tenure.

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

66. I am unable to respond to this question as I cannot recall.

h. ***Did the Haemophilia Society rely on assurances by the Government or individuals in public office on treatment or the risks of vCJD? If so, please provide details, identifying how the Society's approach changed because of those assurances.***

67. I am unable to recall any assurances after this length of time.

Q33: Please detail the relationship the Haemophilia Society had with individual ministers and why it was agreed that separate meetings with ministers could be "damaging to the longer-term goals of the Society"? You may be assisted by HSOC0010536.

68. Any such meetings may have been held with the CEO but I cannot recall with whom or when. Reading the minutes of the Board Meeting HSOC00105036, I can only proffer that we very much respected Lord (Alf) Morris's views and experience on such matters of how the 'establishment' worked so our consensus would be to follow his advice.

Q34: Following the Archer Inquiry, several recommendations were made including the establishment of a statutory committee. What was the Government's response to this? Did they provide any assurances regarding the recommendation of a statutory committee or any of the other recommendations? You may be assisted by HSOC0010524.

69. Chris James, CEO and Bernard Manson, Chair (my successor) may be better placed to answer this. I think the formation of a statutory committee wasn't that straightforward, I seem to think it was going to become a re-jigging of the Alliance. I consider **Exhibits WITN5684004** and **WITN5684005** to be relevant for consideration here.

Q35: Chris James reported that you and he met with the Department of Health [HSOC0010529], and that he anticipated a lack of further core funding from the Department of Health "with or without a recommendation from Lord Archer". Was this meeting a regular occurrence or was it scheduled specifically to discuss funding?

What was said or done to give this impression? Did the Department of Health also give any indication of other matters or proposals which would not be actioned or funded? Please provide as much detail about this meeting as possible.

70. I have no recollection of this meeting or documentation that I can find that goes back to 2009 but I suspect it was a scheduled meeting. I cannot recall detail or dates but Charity funding (Government Grants) was withdrawn for almost all charities at some point. I think these were referred to as Core Grants, Section 64. The loss of this grant had a detrimental impact on the work of the HS in its business as usual activities. Furthermore, I believe that in order to deliver recommendations from the Archer Inquiry, the Haemophilia Society would no doubt have struggled even further with resources. Funding for the Haemophilia Society mainly, either came from legacies (not reliable income), fundraising activities (patchy) or mostly from ring fenced donations from Pharmas or personal doners. Ring fenced, meaning it could only be spent on the specific project that the money was donated for and not for the general running of the Charity. We no longer charged membership as we felt this was discriminatory. However, there is reference in HSOC0010532 that the government offered a new grant after the Archer Inquiry to the HS – I don't recall this or how much it was for. I do however note that within HSOC0010527 there is mention that the HS had received notice from the Department of Health that the £100,000 capacity building grant was under review as part of the Government's review of spending.

5.1 Campaigns after the Archer Inquiry

Q36: How did campaigning efforts of the Haemophilia Society change following the Archer Inquiry? How receptive was the Government/ Department of Health to the Archer recommendations?

71. I am unfortunately unable to recall this detail.

Q37: Did they propose any other alternative measures than the enhanced Haemophilia Alliance referred to in HSOC0010532, page 2? Did the Government provide a reason for not choosing to enact the Archer recommendations? If so, please provide as much detail as possible.

72. I am unable to recall.

Q38: Please provide details on the campaign efforts for the Government to implement the recommendations of the Archer Inquiry. What were the objectives? You may wish to refer to HSOC0010522, page 4 and HSOC0023064, page 8 to assist you.

73. I am unable to recall detail.

5.2 Campaign for an Independent Public Inquiry

Q39: During your tenure, what role, if any, did the Haemophilia Society play in seeking an independent public inquiry? Please set out chronologically the Society's campaign and or involvement in the campaign for a public inquiry.

74. I am unable to recall detail but I think the Society had long tried to press for an independent inquiry. I am unable to provide a chronology because it covers so many years and successive administrations (ie, change in CEOs, and Trustees). Pressing for an inquiry was in addition to providing the many other services the Charity was established to do.

Q40: What discussions were held with the Government with regard to an independent public inquiry? What, if any, reassurances were received from the Government? Did the Society's approach change in light of any such reassurances?

75. I am unable to recall any details of discussions with Government but I suspect we received no assurances that an independent inquiry would happen during my tenure as a Trustee.

Q41: How prominent was the campaign for an independent public inquiry in the Haemophilia Society's campaigning efforts?

76. I am unable to recall detail but the HS would still have had competing demands of delivering business as usual. The Society was not wholly a campaigning organisation but I believe it has always been a goal, since the tragic circumstances of the contaminated blood products have been known about. I have no reason to believe that the Haemophilia Society has never not wanted a public inquiry in respect of the contaminated blood tragedy.

5.3 Other Campaign Efforts

Q42: Please provide details about the Contaminated Blood Campaign. What were the objectives of this campaign? How were the objectives decided? Why was this campaign started?

77. I am unable to recall the precise details of the campaign its objectives or when precisely the campaign started. I recall that HS facilitated other factions/campaign groups, for example Birchgrove/Manor House /Tainted Blood and other individuals to help drive through the Archer recommendations but I also recall there were issues amongst the groups that resulted in my letter to the various campaign groups in 2010 (**Exhibit WITN5684002)**. Chris James and Dan Farthing may be able to recall more detail. I believe the campaign group I am referring to was started because there was a common goal in achieving the inquiry but the Society simply did not have the resources to do it on its own, so I think it was hoped that as a collective more headway would have been achieved. I would state this is my perception and recollection.

Q43: What activities were undertaken as part of the campaign? Who was involved in the campaign? What role did the Haemophilia Society play?

78. I am cannot recall details of activities and I would not have been personally involved in them. HS tried to maintain status quo with factions and support and guide where possible. i.e advise against any illegal activity. HSCO0010527 refers to a letter I sent to the campaign groups (**Exhibit WITN5684002)**.

Q44: What was Under-Secretary of State Anne Milton's role in the Contaminated Blood Campaign? Was she a regular point of contact in the Department of Health? Were any other members of Government involved in the campaign? Did Anne Milton provide any assurances on behalf of the Government? You may be assisted by HSOC0010527, HSOC0023060 and HCDO0000272_004.

79. I am unable to provide further detail. I was never in attendance but I seem to recall some of the campaigners tried to or did achieve meetings without the Haemophilia Society being in attendance. Chris James may be able to comment further.

Q45: Was the Contaminated Blood Campaign successful? If not, please explain the reasons why it was not.

80. I am not sure it achieved what it was originally set up to do because of the difference of opinions, please see my letter at **Exhibit WITN5684002.**

Q46: Please detail the relationships between the Haemophilia Society and campaigning groups such as Tainted Blood and the Manor House Group. What was the general opinion of campaigning groups towards the Haemophilia Society?

81. I think these groups had different approaches because of the impact of HCV vs HIV. Some campaigners were very much into demonstrating whilst I think others preferred lobbying their MPs or press coverage. My perception was that there was lots of history and animosity towards the Society and that they felt the Society was not campaigning strong enough. The Society was not a wholly campaigning organisation nor was it set up for those purposes initially.

Q47: Did the Haemophilia Society often collaborate with campaigning groups and/ or individual campaigners during your tenure? If so, please provide details, including the name of the groups and the objective.

82. I cannot recall specific detail but we did help facilitate the campaign group I refer to above, despite their criticisms of the HS. We helped find and fund venues and probably sent out agendas and facilitated the meetings. I am not aware that the Haemophilia Society collaborated with individuals as such. My perception was we supported all campaigners wherever possible. Again, Chris James might be able to expand.

Q48: Please detail the relationships between the Haemophilia Society and individual campaigners. Were there ever clashes between individuals and/ or groups over the campaigning activities and/or campaigning goals of the Haemophilia Society?

83. Due to the size of the charity, funding and number of activity streams (newly diagnosed children, women and bleeding disorders, aging population, fundraising etc), it wasn't possible to throw all resources at campaigning. My perception was that this became a bone of contention with many of the membership (long before I became a Trustee). Other campaign groups sprang up namely Birchgrove, Manor House then latterly Tainted Blood, Factor 8 and my impression was that the perceived lack of support from the Society frustrated them.

84. HS tried to maintain status quo but there were heated discussions at some meetings. I cannot recall details and only remember commenting at one meeting that we were all in the same boat so we needed to row in the same direction in unison. It wasn't a cohesive group /approach to driving the campaigning forward, or at least that was my perception. I reference my letter to the campaign groups again **(Exhibit WITN5684002)** but there was lots of anecdotes and tales about personal attacks and

criticisms. I cannot be more specific or recall the individuals or groups at this length of time.

Q49: Please explain why the Board of Trustees decided not to support the submission referenced in HSOC0010539, despite acknowledging that it could be sure the views expressed represented those of those in membership affected by contaminated blood.

85. I think, reading the paragraph, that there is a typo and it should have read; 'as it *couldn't* be sure the views represented the relevant members of the membership of the HS'. I would need to see the submission and Chris James' notes to have more clarity.

5.4 All Party Parliamentary Group

Q50: Please explain what the goals and priorities of the All Party Parliamentary Group on Haemophilia and Contaminated Blood ("APPG") were. To what extent, if any, did the APPG achieve these goals during your tenure?

a. How were the goals set?

86. I am unable to answer this question and cannot recall if I had any involvement.

b. What was the level of involvement of the Haemophilia Society in the APPG?

87. I do not have enough recall/knowledge/documents to comment. The APPG are not selected by the HS. The HS acts or at least acted as the secretariat I think during my tenure. Membership representation would have attended some of these meetings/ events. Current and past CEOs will be able to provide more detail. I think the APPG were able to bring the issue of contaminated blood to PMQs and lobby for change or support to holding an inquiry or ensuring equitable treatments. Some MPs were/are very prolific in their lobbying I think but I cannot recall attending any APPG meetings during my tenure but Chris James CEO may be able to comment further.

Q51: Who was in the APPG and how were they selected? Please explain what the Group discussed and achieved during the course of your tenure at the Society.

88. I cannot recall who was on the APPG during my tenure. I do not know what was table for discussion or what achievements were attained.

Q52: How effective was the APPG? Did it lead to or produce results/ assurances from the Government? Did the APPG assist the Haemophilia Society in achieving any of its goals?

89. I am unable to recall after this time how effective the APPG were, what if any results or assurances were achieved in the Societies goals.

Q53: Please outline the role and the responsibilities of the Chair of the APPG. Please identify any other key individuals in the APPG who held roles and outline what those roles involved and the responsibilities they had. Do you consider those roles to have been performed satisfactorily?

90. I am unable to answer this question as I cannot remember who may have been on the APPG at the time of my tenure.

Q54: To what extent, if any, was the position of the APPG informed by the views of the Society's membership? Did the views of the APPG differ from the views of the Haemophilia Society Board of Trustees, as you understood them?

91. I am unable to answer as I cannot recall what the position was during my tenure. I cannot recall if any of the Trustees attended any of the APPG meetings but Chris James may be able to recall. I am afraid to say I have no recollection of the APPG and Haemophilia Society activities at that time.

Section 6: Interaction with Trusts and Schemes

Q55: During your tenure, what was the Haemophilia Society's position, if any, with regards to the financial assistance structure for haemophiliacs who were infected with hepatitis and/or HIV as a result of contaminated blood products? If this changed over time, please detail when and why.

92. I am unable to recall what the Society's position was during my tenure. We were not directly involved with how the financial assistance was administrated.

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

93. I have no recollection of what was communicated or what responses were received.

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

94. I have no recollections on being sighted on any statements or assurances.

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

95. I have no recollection.

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

96. I am unaware of any of this detail or how we would have presented these schemes to those affected members. I am making an assumption that those affected may not have been members of the Society, or at least not all, and that they would have been making their own applications.

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

97. When I joined the Society as a member I was unaware of these trusts and schemes. When I was a Trustee I am aware that we had some members on the MacFarlane Trust and that one of the Society's Trustees, Anne Hithersay had been involved with the Macfarlane Trust previously. The Society was also involved in appointing Society membership representatives to the MacFarlane Trust. We also had a volunteer in the Society who I think volunteered for the MacFarlane Trust and may have been a beneficiary of the MacFarlane Trust. I cannot recall if the Society presented any criticisms to Government in respect of these schemes.

98. The Society's Trustee appointees were reduced from 4 to 2 towards the end of my tenure.

6.1 Relationship with the Macfarlane Trust

Q56: Please detail your involvement with the Macfarlane Trust, and the relationship between the Haemophilia Society and the Macfarlane Trust.

99. During my tenure as Trustee, my involvement was limited. We (HS) sought interest from members to sit on the MFT Board. One of our volunteers also volunteered for MFT. The relationship between the CEOs of the MacFarlane Trust and the Haemophilia Society were convivial I believe. I occasionally met with both the Chair and the CEO of the Macfarlane Trust, but I cannot recall or have any evidence of any specific meetings. I do not believe that the Haemophilia Society had any influence over the operational activities of the MFT.

100. Having found some emails from 2011 I am reminded that in early July 2011, Peter Stevens (I believe had been a Trustee of the Macfarlane Trust previously, and was involved with setting up of Caxton) contacted me to ask if I could help with the process of appointing trustees to Caxton. I think the person that had originally been asked was unable to assist and my name had been put forward by either Martin Harvey or Roger Evans. My role to act as an independent assessor and ensure that the interview panel (I am unable to recall who the panel was made up of apart from Peter Stevens) conducted structured interviews in a fair and equitable manner. I was not part of the selection panel. I was still the Chair of the Haemophilia Society at this time My involvement was declared to the CEO and Chair of Macfarlane Trust and to the CEO and Board of the Haemophilia Society.

101. Around the end of July 2011 Martin Harvey asked if I would help with the selection process for a new Chair of the Macfarlane Trust as Christopher Fitzgerald was standing down the following year. As is documented, the process was run but there was a dispute within the Board of the Macfarlane Trust and the process was run again in 2012. Looking back I am reminded that I was partially involved in again in 2012 because of the work I had done the previous year with the adverts and the selection criteria and scoring matrix for shortlisting. However, I had stood down as Chair of the Haemophilia Society the previous November (2011) and by the time the interviews came around I had started a new contract with the City of London Police and was unavailable to attend as an independent assessor. A former work colleague of mine who had the relevant experience acted as assessor at interview stage in 2012 for the Chair of the Macfarlane Trust. I had no involvement in the selection process for the CEO of Caxton when Martin Harvey retired due to ill health.

102. Apart from that I had no involvement with any of the other Trusts other than meeting socially with members who attended WFH events. I personally cannot recall the Society being approached by members to lobby for funds or changes to the schemes.

Q57: Please outline the role that the Haemophilia Society played in the operations of the Macfarlane Trust. To what extent, if any, did you or other members of the Haemophilia Society have an influence over the running, functions, processes, aims or objectives of the Macfarlane Trust?

103. We did appoint HS members as Trustees, however the HS had no role in the operations of the MFT or influence over the running, functions, processes, aims or objectives of the Trust.

Q58: Please confirm if you attended Macfarlane Trustees meetings and any other(s) you attended and, if so, please also confirm your role at those meetings. If you were a Trustee, please explain how you came to be appointed and for what period you were in that role?

104. I do not recall attending Macfarlane meetings in my role as Chair of the Haemophilia Society. As above, I assisted with the selection process for the Chair of the MFT in 2011/12.and I recall attending part of a Trustees meeting at the MFT to discuss the recruitment process/results and selection process for the Chair of Macfarlane in 2011 when the Board decided against appointing a candidate. I had no involvement with anything else. I did have discussions with the CEO of MFT over the phone, about a HS Trustee (now deceased) and their behaviour at a Something for Weekend event (this was a MacFarlane Trust event – details unknown to me) which led to the resignation of the Trustee from the Haemophilia Society. Apart from that I can offer no more context. I was and never have been a Trustee of any of the AHOs.

Q59: How often did the Haemophilia Society and the Macfarlane trust meet? Please detail how often the two organisations communicated.

105. I cannot recall in detail. I think the CEOs would have telephone discussions, emails and the CEOs and Chairs would meet occasionally but I cannot recall the detail of the meeting or the frequency. We may have met to discuss Society Trustee appointments, particularly when our numbers reduced from 4 to 2.

Q60: Please detail the overlap between the Macfarlane Trust and the Haemophilia Society, including the overlap in personnel, roles and responsibilities. Do you consider that there was a sufficient level of separation between the Macfarlane Trust and the Haemophilia Society to ensure tFMFT

hat each organisation adequately supported its recipients and members respectively?

106. There was no overlap in respect of staff personnel. I consider that there was enough separation between the two organisations. The aims and objectives were two different things and provided differing support to their members. The Society's membership was bigger and more diverse (ie our membership were not necessarily impacted by contaminated blood products). I can only recall one of the Societies Trustees being on the Board of the MFT but I am not sure if that resulted in any conflict of interest because of the nature of the two different organisations. I seem to recall our Trustee retaining a great deal of confidentiality of what he was involved with in the MacFarlane Trust.

Q61: What involvement did the Haemophilia Society have over the selection of a candidate for and the appointment of the Macfarlane Trust chairperson position?

107. The HS had no involvement with the appointment of the MFT Chair of Trustees. However, around the end of July 2011 Martin Harvey asked if I would help with the selection process for a new Chair of the Macfarlane Trust as Christopher Fitzgerald was standing down the following year. As is documented, the process was run but there was a dispute within the Board of the Macfarlane Trust and the process was run again in 2012. Looking back I am reminded that I was partially involved in again in 2012 because of the work I had done the previous year with the adverts and the selection criteria and scoring matrix for shortlisting. However, I had stood down as Chair of the Haemophilia Society the previous November (2011) and by the time the interviews came around I had started a new contract with the City of London Police and was unavailable to attend as an independent assessor. A former work colleague of mine who had the relevant experience acted as assessor at interview stage in 2012 for the Chair of the Macfarlane Trust. Neither she or I had any direct involvement with the appointment, those decisions were down to the Macfarlane Trust. The assessors role was to ensure the process was fair and transparent.

108. ***Q62: In your view, was the recruitment and appointment process fair and reasonable in selecting a suitable chairperson for the Macfarlane Trust? You may wish to refer to MACF0000025_012 for a review of the process.***

109. I can't remember why I was approached to conduct the recruitment process and not John West who was a recruitment consultant that had been used previously I think by the Macfarlane Trust. As outlined above I had been asked to act as an independent assessor in early July 2011 in the appointment of trustees to the Caxton Foundation. I may have been asked to get involved because the process had been considered appropriate and successful for the Caxton trustees. I believe the process was fair and reasonable as set out in my proposal (starting on page 6 of ***MACF0000025_012).*** This structure is considered to be fair and transparent and as far as I was aware was approved by the Board at the Macfarlane Trust. As is documented they chose to make an appointment of the Chair in 2011 and the process was run again in 2012. Partly with my input in the initial stages and then at interview stage the independent assessor role was fulfilled by a former work colleague of mine who had considerable experience in recruitment and selection and was also an equality and diversity manager of some years standing within the police service. The Haemophilia Society had no involvement with the appointment of the Chair of the Macfarlane Trust in 2012.

Q63: In your view, was the appointment process fair and reasonable in appointing a Haemophilia Society Trustee to the Board of Macfarlane Trust? You may wish to refer to HSOC0010523.

110. Yes it would appear so and the Board of MFT reached a consensus on the matter. However, I cannot recall the interviews and the panel that followed. To clarify; my recollection is that Philip Dolan was the last person that sat as a Trustee on both Boards. I think we moved to the Haemophilia Society Trustees appointing Haemophilia members to the Board of MacFarlane so they was not a Trustee on both committees. I cannot recall why this became a rationale though.

Q64: In May 2005 it was decided that the Macfarlane Trust Board would be made up of four Department of Health (DoH) appointees, four Haemophilia Society appointees (including two user Trustees) and four Macfarlane Trust appointees. As to this:

- ***a. How did the introduction of four Haemophilia Society Trustees to the Macfarlane Trust Board, two of which being User Trustees, affect the relationship between the Haemophilia Society and the Macfarlane Trust?***

111. I was a relatively new Trustee of the Haemophilia Society at the time so I am not aware there was any impact.

- ***b. Were you satisfied with the make-up of Trustees? If so, why and if not, why not?***

112. I had no reason or complete understanding of the background of these appointments historically so I cannot comment on this question.

c. What was the importance of having DoH and Haemophilia Society appointees on the Macfarlane Trust Board?

113. I am not in a position to comment as this appears to be correspondence from my predecessor and I was relatively new in the role of a Trustee with now prior knowledge at the time of the MacFarlane Trust.

Q65: In the Haemophilia Society Winter Magazine 2008/9 [HSOC0023065], the position of a Haemophilia Society appointed Trustee on the Macfarlane Trust Board was advertised.

- ***a. Please explain how a Haemophilia Society appointed Trustee for Macfarlane Trust would assist with the 'development' and 'management' of the Trust.***

114. I am not sure I can answer this question as the CEO wrote the piece, but I think the HS always felt it important to have the relevant membership represented at the table to ensure issues that affected them were discussed and raised.

b. How did a Haemophilia Society appointed Trustee act as a 'vital link' between the two organisations?

115. I assume that in theory if there were similar issues that needed addressing with the DoH we could ensure a united front and if necessary cohesive correspondence. I cannot think of a specific topic however to demonstrate this.

Q66: At a Haemophilia Society Trustees meeting on 4 March 2008, it was noted that concerns were raised as one of the Department of Health's appointments to the Macfarlane Trust's Board was not a qualified Social Worker [HSOC0010514].

a. How often would concerns regarding the composition of the Macfarlane Trust Board arise?

116. I have no recollection of how often or what concerns were raised about the composition of the Macfarlane Trust Board.

b. Was it policy or common practice to inform the DoH and Macfarlane Trust of concerns relating to the formation of the Macfarlane Trust Board?

117. I am not aware that it was.

c. When you raised concerns with the Macfarlane Trust, did you feel the Macfarlane Trust addressed them adequately?

118. I cannot recall any specific instances but I think if we had then they would have been answered if not necessarily addressed.

Q67: At the Haemophilia Society Trustees meeting on 24 February 2010 [HSOC0010524], Phil Dolan expressed concerns that the Macfarlane Trust Board of Trustees was to be reduced. Did you agree with Mr Dolan's concern that a reduction in appointees on Macfarlane Trust's Trustee Board would lead to Haemophilia Society being less represented? If so, why was this a concern? If not, why not?

119. If my memory serves me well I think the Board agreed that this was not something we could influence as it was a change to MFT's governance arrangements and that other representation from other membership on their Board was also being reduced on a pro-rata basis. So no, I think the Board agreed that it was not of serious concern to the Haemophilia Society.

Q68: In a report titled 'Proposed future governance arrangements for allocating grants and reserves' on 15 September 2012, [MACF0000025_032] Roger Evans suggested methods to appoint new members to the National Support Services Committee (NSSC) Board.

a. Why were you considered for selection as an independent third party for the NSSC member appointment process?

b. Did you take up this role? If so, how did it operate?

120. I have reviewed [MACF0000025_032] and pages 12 to 19 relate to a meeting held on 31 August 2012. I find my name mentioned on page 16. I cannot however recall ever having a conversation with Roger or anyone else from the Macfarlane Trust and I do not recall being involved with any selection process to appoint members to their NSSC panel.

121. I also note that at 578.12 of [MACF0000025_032] it refers to a report from the Chairman on progress and time table for the appointing of a CEO. This minute is dated 24 September 2012. By this time I had taken up full time employment with the City of London Police and was not involved with this recruitment.

Q69: In a Haemophilia Society Parents Support Task Group meeting on 3 February 1998 [HSOC0026799], it is noted that the Macfarlane Trust were approached concerning the lack of support available for teenagers infected with HIV and HCV.

a. Why were there concerns that there was not enough support for teenagers with HIV and HCV?

122. I am unable to answer this question. Despite it being discussed at this meeting I do not recall the discussion but note that the issue was brought up by Lucy McGrath the Hep C worker at the Society at that time and GRO-A who I think must have been another parent on the group. Lucy stated that there was a gap in services and no literature available at that time. As I was not on the Board at that time I am unable to comment further on what the Society was providing at that time for teenagers affected by Hep C.

b. How were these concerns handled by Macfarlane Trust?

123. I am unable to answer this as I would not have been involved with taking the issues up with the Macfarlane Trust. I note that the minutes say that GRO-A was talking to Fran Dix at the MFT about HIV issues not Hep C.

Q70: How did the Haemophilia Society and the Macfarlane Trust assist beneficiaries with receiving disability benefits? Did you think this assistance was sufficient?

124. I do not know how the MFT assisted in benefit applications. I think Nick Fish was the benefits officer back then at the Macfarlane Trust. I am not aware that the Society and the Macfarlane Trust staff discussed these issues. To the best of my knowledge, the Haemophilia Society for a number of years provided support to members in applying for benefits. In particular, I think this was mainly for parents applying for DLA for children but I cannot be sure. I think this was mainly carried out over the phone but I do not know about the volume of calls or the content. I am unaware if the benefits advisor attended any meetings. However, cuts to HS's funding and expertise impacted on this greatly. I think it was sufficient at the time but this could be best answered by the former benefits advisor. I believe by the time I ended my tenure the Society no longer had a dedicated benefits advisor.

Q71: At a Haemophilia Society Trustees meeting on 10 September 2008, it was noted that the Haemophilia Society and the Macfarlane Trust worked together to provide a survey to see what problems there were in receiving disability benefits for beneficiaries [HSOC0010520].

a. What were the results of this survey?

125. I note the minutes say 'were seeking' to survey the membership. I appear not to have been in attendance at this meeting and am unable to comment further. The issue may be raised in a later set of minutes if these can be found.

b. Please give details as to whether this survey assisted beneficiaries in receiving disability benefits? If so, how? If not, why not?

126. I am unable to answer this question given that I am unsure if the survey went ahead. The answer may lie in a later set of minutes if they are available.

Q72: At a Haemophilia Society Trustees meeting on 11 January 2005, it is noted that a sub committee was to be created to meet with registrants and address concerns, including the request for the Haemophilia Society to act as a 'watchdog' for the Trust [HSOC0029689_058]. This same view was reflected in the 'Service Report' by John Morris dated 25 February 2005 , who stated that there was pressure on the Haemophilia Society by some beneficiaries to become a 'watchdog' for the Macfarlane Trust [HSOC0020057]. Please explain:

a. What is meant by the term 'watchdog' for the Macfarlane Trust?

127. I am not sure what was meant by this term. I think the meeting that is referred to would have been only my second or third as a Trustee of the HS and so I wasn't aware of these issues at the time.

b. Why was there pressure on the Haemophilia Society to act as a 'watchdog' for the Macfarlane Trust?

128. I am afraid I do not know what the issues were and I wasn't personally involved with any of these discussions that took place. It would appear that Trustees like Bill Payne who I think was impacted by these issues personally, were going to meet with the registrants to discuss. I was not involved nor had I access to these discussion forums.

c. Please detail any action taken as a result of this comment.

129. I am unable to comment if any action was undertaken. If minutes were taken at the subgroup / meeting mentioned above they may disclose more detail but I was not involved in this particular discussion/meeting. I believe that much of what was discussed about the Macfarlane and Skipton had input from Trustees who were closer to issue than myself who had no experience of the issues the registrants were taking. The Board had a mix of individuals with different experiences and skills and some were involved with the Trusts because of their viral status.

Q73: Please set out your role and responsibilities as an Independent Assessor for the Macfarlane Trust. You may wish to refer to MACF0000025_004 to assist you.

a. Please discuss your involvement with the recruitment process for the Chair of the Macfarlane Trust. You may wish to refer to MACF0000025_012 to assist you.

130. As mentioned above in my answer to Q56 & 61 I was approached to act as an independent person (Independent Assessor, as described in the minute of the Special Meeting of the Board of MFT Trustees MACF0000025_004) to run the recruitment process for the MFT, to ensure that it was fair and equitable and that a structured interview process would take place. I was not involved in selection or interviews (to the best of my recollection). I did however help draft the questions and the scoring matrix for shortlisting and interviewing. The processes, the same criteria and questions were applied to all candidates. In my email to Martin Harvey dated 17 January 2012, I can see that I have offered a proposal and outline the process for recruitment. I considered my involvement to be independent in as much as I was not going to be in position to make or influence any appointments as this would have fallen to the Macfarlane Trust panel as outlined in the various stages of the proposal. The process was suggested to avoid any bias towards candidates. I was not involved

in any discussions that are alluded to in the meeting mentioned at 525.11 of MACF0000024-004 but was called into the meeting to discuss the process held previously in 2011 and then I left the meeting. As outlined above I did not assess the 2nd round of interviews in 2012 as I was unable to due to work commitments.

6.2 Relationship with other Trusts and Schemes

Q74: Please detail the relationship between the Haemophilia Society and the remainder of the Alliance House Organisations ("AHOs"), namely:

a. The Caxton Foundation;

b. The Skipton Fund;

c. The Eileen Trust; and

d. The MFET.

131. In respect of all of the above AHOs, I believe the relationship was based purely on fact that some (not all) of our membership were registrants. The commonality being haemophilia and contaminated blood products. The trusts were however independent of the HS. There may have been some cross over of boundaries relating to issues with the DoH such as recombinant treatments for all as an example, and we may have supported some of their events. I cannot recall any meetings or correspondence with any of the above apart from the Macfarlane Trust, as previously mentioned. The Caxton Foundation only came into being, I believe in 2011 either towards or after the end of my tenure as a Trustee of the Haemophilia Society. I cannot offer more comment than that as I am unable to recall.

Q75: What did the application process for infected and/or affected individuals applying to each of the AHOs entail?

132. I do not know. The HS had no involvement in the application process but I am aware that registrants were not always happy with the process. I do not believe the HS supported members with applications but the CEO might know different.

Q76: In your experience, were the application criteria to each of the AHOs transparent and accessible?

133. I do not know but I am aware from conversations and anecdotes at social events, that some thought it was not. I cannot say if these comments were from registrants who were also members of the HS. Not all registrants were members of the HS. I cannot recall which individuals I heard this from but there was a general perception I think that this was the case.

Q77: Was practical support and assistance provided by the Haemophilia Society and each of the AHOs to applicants when making applications? If so, what was this and was it sufficient in your view?

134. I do not know if the HS provided support to applicants, I do not believe it did. I cannot comment what support or assistance was given by the AHOs as I was not involved with them in this capacity at any time.

Q78: Did the Haemophilia Society reach out to the haemophiliac community to advertise the existence of the AHOs? If so, how?

135. I do not believe so.

Q79: What, if any, observations do you have about the decision-making processes of the AHOs when considering applications for financial support?

136. I am unable to comment as I was not involved with any of the AHOs in any of this capacity.

Q80: How were applicants to the AHOs treated during the application and decision-making process?

137. I do not know as I was not involved in the application and decision-making process of AHOs.

Q81: In your view, were decisions by the AHOs made in an efficient and timely manner?

138. I am unable to comment as I was not involved with any of the AHOs in any of this capacity.

Q82: In your experience, were applications decided in a consistent manner? If not, please describe any inconsistencies you are aware of?

139. I am unable to comment as I was not involved with any of the AHOs in any of this capacity.

Q83: In your experience, were adequate reasons given by the AHOs when applications were refused?

140. I am unable to comment as I was not involved with any of the AHOs in any of this capacity.

Q84: During your time as a Trustee and Chair, did the Haemophilia Society receive any feedback or comments concerning the application process to any of the AHOs? If so, what were they?

141. I am only aware of anecdotal comments that members were not happy with the process – and what they could claim for. I understood to it be intrusive, means tested and further complicated by so many trusts dealing with affected individuals and then separate schemes for families/widows. It all seemed very divisive and far too complicated, certainly from the outside and even more so when Caxton was introduced after I completed my tenure. This is my personal view as due to my circumstances I had no personal dealings with these organisations.

Q85: Please detail the opinion of the Haemophilia Society membership on the efficacy of the above mentioned AHOs.

142. Please see my answer above to Q84.

Q86: Did the Haemophilia Society have a similar level of involvement with the other four AHOs as it did with the Macfarlane Trust? Please detail any involvement or influence the Haemophilia Society had with each of these organisations, including whether previous or current members of the Haemophilia Society sat on the Boards of these organisations.

143. I cannot be sure in answer to this question but I think the HS really only had interaction with MFT and as far as I am aware the HS's representation was on the MFT only but that is my recollection. I refer to my responses above.

Q87: Please comment on any difficulties or shortcomings you encountered with the trusts and schemes during your time at the Haemophilia Society.

144. I am unable to comment and cannot recall specific issues.

Q88: Please comment on the efficacy of the Alliance House Organisations ("AHOs") you interacted with, and whether, in your view, they achieved their aims and purposes.

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

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

145. I am unable to comment save for the comments made above. It appeared to me to be complicated having a number of AHOs and that it got too difficult to administer and pick them apart.

6.3 Skipton Fund

Q89: The Haemophilia Society contacted the Department of Health about the Skipton Fund appeals process and proposed changes which were not adopted

[HSOC0019926_003, page 2]. What were these proposed changes? Why were these changes not made by the Department of Health?

146. I have no record or recollection of the letter or what the proposals are. Roddy Morrison was Chair & Margaret Unwin was CEO at that relevant time so I am unfortunately unable to assist with this point.

Q90: Did the Haemophilia Society often contact the Department of Health about concerns with the Skipton Fund and/or the other AHOs?

147. I do not recall specific contacts with the DoH on this but I accept it would have been likely if we had been asked for support by the membership.

Q91: At a Haemophilia Society meeting on 30 March 2004 , Trustees were concerned that applicants to the Skipton Fund were going to be asked to sign waivers to ensure that they did not initiate proceedings against ministers [HSOC0020085_003].

a. The document notes that the Haemophilia Society wrote to Peter Stevens addressing their concerns about the waiver; what was the response from Peter Stevens?

b. What was your position on the waivers that applicants may have to sign?

148. This was prior to my tenure as a Trustee at the HS so I was unaware of the correspondence. I became aware of the waiver issue after I became a Trustee and I would agree that applicants should not have signed them, although I think some did out of desperation. This is my personal view as I was not on the Board of Trustees at this time.

Q92: During your time as a Trustee and Chair, did the Haemophilia Society receive any feedback or comments concerning the payments from the Skipton Fund? If so, what were they? [HSOC0012286].

149. I am unable to answer. I consider the CEOs best placed to respond to this point.

Q93: At a Haemophilia Society Trustee meeting on 25 June 2004, it was noted that there were concerns that a re-structuring of the Macfarlane Trust would lead to another delay in payments from the Skipton Fund [HSOC0020067]. Please explain:

a. What reason was provided for the delay in providing the first HCV payments from the Skipton Fund?

b. Were there any delays to payments caused by the restructure of the Macfarlane Trust? If so, how did this impact the Haemophilia Society members and the Skipton Fund beneficiaries?

150. a) and b) I am unable to answer as I was not on the Board at the time.

Q94: At the same Haemophilia Society Trustee meeting on 25 June 2004 , there was a growing concern among the Haemophilia Society Trustees that the newly established Skipton Fund did not include the bereaved and that the cut-off date for eligibility was the July 5 2004 [HSOC0020067]. Please explain:

a. What, if any, discussion occurred with the AHOs regarding the decision not to provide payments to the bereaved community.

b. What, if any, discussion occurred with the AHOs regarding the July 5 2004 cut-off date.

151. a) and b) As per my answer to Q93, I am unable to answer as I was not on the Board at the time.

Q95: As of 2004, the Haemophilia Society decided to continue campaigning for the widows and bereaved community to receive HCV payments and to campaign against the cut-off date of 29 August 2003 [page 4, HSOC0020074] . Please explain:

a. How was your campaign for payments to the widowed and bereaved community received by the AHOs?

b. Why did Haemophilia Society deem the cut-off date of 29 August 2003 as 'immoral'?

c. Was this view shared by the AHOs?

152. a) and b) As per my answer to Q93 and Q94, I am unable to answer as I was not on the Board at the time.

Q96: At a Haemophilia Society Trustees meeting on 9 August 2006, it was noted that the Haemophilia Society had written to the DoH proposing changes to the Skipton Fund Appeals process [HSOC0019928]. Please explain:

a. Why did the Haemophilia Society suggest changes to the Skipton Fund Appeals process?

b. What were the proposed changes?

c. Why were the proposed changes denied?

153. In answer to questions a) – c), I unfortunately cannot recall the detail of suggested changes to the Skipton Funds Appeal process. I note there were issues with a fraud at the Skipton that may have impacted on this, however this is speculation.

Q97: In 2010, a Government review took place regarding the support available to those affected by contaminated blood in the following areas: the level of financial support for dependents of those infected with HCV; the 'mechanisms' for ex-gratia payments for HCV and HIV; the provision of insurance for those infected; the issue of prescription charging for those infected and the provision of access to nursing in the community.

a. Please explain if you, and other Trustees of the Haemophilia Society, believed a review of the support available from the Skipton Fund and Caxton Foundation was necessary. If so, why? If not, why not? You may wish to refer to the Haemophilia Society Winter Magazine 2010/11 HSOC0023061 for information on the review.

154. Yes, I believed that a review of the support available from the Skipton Fund and Caxton Foundation was the right thing and I think the Board and the membership were content with the Terms of Reference outlined in the magazine. As an individual I did not have any personal involvement with the Trusts' administration but as I have mentioned above I am aware that registrants struggled with the layers of complexity.

Q98: The Haemophilia Society Autumn Magazine 2011 highlights a meeting on 29 June 2011 between representatives from Haemophilia Society and Anne Milton MP to discuss the Government review and new arrangements for support for those affected by contaminated blood [HSOC0023060]. Please explain:

a. Why did Haemophilia Society approach Anne Milton to review the Skipton Fund Stage 2 Applications and what was the outcome?

b. What concerns were raised over the Skipton Fund application rejections? How were these concerns handled? Were they rectified?

c. Why was it decided that the Caxton Foundation application process needed to be amended and what was the outcome?

155. a – c) I had stepped down in my position as Chair by this point and unfortunately cannot recollect such a meeting or what led to this meeting so I am unable to comment.

Q99: In the Haemophilia Society Winter Magazine 2012/13 , it notes that regular meetings were set up with the DoH following the Archer Inquiry, so that the Haemophilia Society may express their issues directly [HSOC0023057]. Please explain:

a. What were the issues around access to Skipton Fund and Caxton Foundation that were raised to the Secretary of State?

b. What was the DoH's / Secretary of State's response to the issues raised?

c. Did you share these concerns with either the Skipton Fund or the Caxton Foundation? If so, what was the response? If not, why not?

156. a) – c) I was no longer on the Board at this time so am unable to comment.

6.4 Criticisms and complaints of the AHOs

Q100: A letter from Liz Carrol to a member of the Haemophilia Society, concerning the vote of no confidence in the Macfarlane Trust and their CEO, outlines reasons why such a vote would not be beneficial, but adds 'Our Board of Trustees are aware of the dissatisfaction that you and those beneficiaries you represent hold with the Macfarlane Trust'. At the bottom of the document it indicates that it was a statement made on your behalf [HSOC0029441_002]. Please answer the following:

a. Why was there a call for a vote of no confidence in the CEO and Board of the Macfarlane Trust from a group of beneficiaries?

b. Was this view reflected by Trustees of the Haemophilia Society? If so, how?

c. What were your views on this call for a vote of no confidence?

d. What dissatisfaction towards Macfarlane Trust were the Trustees of Haemophilia Society aware of?

157. I am unable to find a copy of the letter GRO-A (as representative for the Beneficiaries of the MFT) which was sent to me and others, that outlined their grievances. I assume that a copy is held by the Society as it was also sent to Liz Caroll and Bernard Manson. I have appended my correspondence to GRO-A (**Exhibit WITN5684007**). I advised both Bernard and Liz that I would not respond to the issues outlined in GRO-A's letter as I was no longer a Trustee but was still referred to as the Society's representative on the Alliance, although by that time I do not think there are had been anymore Alliance meetings that I was invited to.

158. Without the letter from GRO-A, I am unable to recall what the issues were. As I was no longer a Board member at the HS and whilst I was still down as Chair of the Alliance, I do not think we had had any meetings and I do not think I attended any after this date. I am therefore unfortunately unable to answer these questions. My vague recollection was that the letter contained a long list but I think the general theme was a lack of confidence in the management and Trustees of the Macfarlane Trust.

Q101: In a 'Service Report' by John Morris dated 25 February 2005, Mr Morris stated that 'an overwhelming amount of dissatisfaction with the Macfarlane Trust is being expressed through the Trust's and Society's website discussion forums' [HSOC0020057]. Please answer the following questions:

a. What views/comments do you recall being made about the Macfarlane Trust?

159. As outlined in Q72. I do not recall being sighted on these comments as they were confidential forums to which I did not have access. I have no recollection of these comments being shared with me verbally.

b. What was your view on these comments?

160. I am unable to comment as I do not know what these comments were.

c. Were these comments a fair and reasonable view on the operations of the Macfarlane Trust? If so, how. If not, why not?

161. As above I was not sighted on the comments and therefore cannot comment.

d. Were these views also expressed by the Trustees of the Haemophilia Society?

162. I do not know what the views of the other Trustees at this time were.

6.5 Tanner Fund

Q102: The HSOC established the Tanner Fund to assist individuals with low income to purchase necessities relating to their blood disorders. Did the Haemophilia Society direct registrants with infected blood conditions to the AHOs for necessities such as these? You may wish to refer to [HSOC0023074] and [HSOC0019926_003].

163. The Tanner fund was a long-standing fund that had limited ring fenced funding. I think that a lot of the requests came from low income families with children who would not have access to the MFT or the Skipton Fund because they would have been of an age or have been fortunate enough not be affected by contaminated blood. I cannot recall details as these would have been administered by the staff with requests being approved possibly by a Trustee on the Haemophilia Society finance sub- committee.

Section 7: Financial Activities

7.1 Fundraising Activities

Q103: How, if at all, did the Haemophilia Society's fundraising activities develop over your tenure? Please provide as much detail as possible about the fundraising strategies employed.

164. I am unable to recall in detail but we had a number of fundraising managers during my tenure. Examples of fundraising initiatives will be found in editions of the HQ or Bulletin magazines, but would have included marathons, swimming, sky diving. HS would have applied to trusts for trust funding. I cannot name any particular trust that the HS would have applied to but trust funding is common within the charity sector. Many trusts have been set up by philanthropists with private sustainable funding. The Garfield Weston Foundation for example. Legacies also provide funding to charities but cannot be relied on as regular income. The HS would have sought grants from Pharmas to deliver specific projects. For example, Novo Nordisk may have supported work around inhibitors in children. There would have been local group fundraising initiatives, swims, fun-runs. I do recall the Board reaching a consensus to employ a cold calling campaign, however I wasn't keen on this idea of fundraising and probably voted against it. I certainly received at least one personal complaint from former Trustee who contacted me on personal phone about this approach and a decision was therefore made to pull this means of fundraising.

Q104: What proportion of the budget of the Haemophilia Society was raised through fundraising during your tenure?

165. I cannot recall this budget detail but it could be found in annual reports if available.

Q105: Were Society members aware of where the money they raised or donated was being spent? How often were members asked to raise or donate funds?

166. I believe so. We would announce at AGMs, publish in our accounts and in the HQ etc. We would have done at least one 'annual ask' which would have been sent out to the membership to ask for support in fundraising. I think this still happens, possibly when the annual notification for the service of remembrance and the Christmas card leaflet goes out. Forthcoming and past events are usually promoted in HQ. I do not have any further detail.

7.2 Relationship with Pharmaceutical Companies

Q106: 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.

167. This is a question best addressed to the CEO but we would have ring-fenced funding from Pharmas to run particular projects as outlined in the above example of work/projects on inhibitors by Novo or some Pharmas may have helped fund publications costs of the HQ magazine. We would usually ask for funding from more than one to ensure there was no bias. I do not believe we relied on them supplying blood products to the HS however. They may have done to the WFH. Some of that funding may have funded part or all of a staff post but I cannot recall any specific Pharma funding a specific staff post. I am unable to comment on the value of funding received during my tenure but I think some of this detail may be found in the annual reports.

Q107: 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.

168. Mainly through the CEO and Pharma Representatives with conduits perhaps to Haemophilia Centres.

Q108: Was the Haemophilia Society allowed to determine where the funds from the pharmaceutical companies were directed, or was the money given for a specific purpose? What, in your view, were the motivations or expectations, if any, of pharmaceutical companies who donated to the Haemophilia Society? Was there an expectation that the Haemophilia Society would provide anything in return and if so, what?

169. I believe the HS was allowed to determine where the funds were directed but the CEO would have more knowledge than I. I think there would be certain Pharmas who produced products like a bypassing agent for inhibitor treatment that no other Pharma produced so it would make sense for that funding to be ringfenced for a project on inhibitors. This is just an example and I cannot recall specifically in any more detail, given the time passed. It was not my perception that the Pharmas expected anything in return. I do not believe we had any influence in what treatments the Centre directors would give their patients. Before I was a Trustee I personally approached some Pharmas to seek funding for me to attend WFH. We would acknowledge Pharmas support in HQ or publications if they had support the work that is all.

Q109: 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?

170. The CEO of the HS would be better placed to answer. My recollection was that the funding varied from year to year. This might be reflected in the market value of blood product consumption in the UK but I cannot recall after this period of time.

Q110: A number of the Haemophilia Society Haemophilia Quarterly issues ("HQ") ended with thanking a range of pharmaceutical companies for their "valuable support" including Baxter Bioscience, Bayer, CSL, Behring, Grifols, Novo Nordisk, and Pfizer Pharmaceuticals [e.g. HSOC0023064, page 19]. Was that record a requirement of their funding? What was agreed in this regard? If so, how was this agreed?

171. I am not sure if it was a requirement, but I think this was just a polite thing to do and it demonstrated that there was no bias towards one Pharma more than the other by the HS. I believe it demonstrated transparency and an acceptable thing to do.

Q111: Did the Haemophilia Society publish or disseminate any articles or publications in exchange for or with the expectation of receiving financial contributions, or any other benefit, by pharmaceutical companies? If so, please provide details of the nature of these articles or publications.

172. Not that I am aware.

Q112: Did the Haemophilia Society refrain from publishing or disseminating any articles or publications in exchange for or with the expectation of receiving financial contributions, or any other benefits, from pharmaceutical companies? If so, please provide details on the nature of these articles or publications.

173. We would not have published or disseminated articles in exchange or with sole expectation of receiving funds or benefits. We were not led or coerced by any Pharma during my tenure to produce articles in favour of their products.

Section 8: Variant Creutzfeldt-Jakob Disease

Q113: In relation to vCJD, the Society raised the idea of pre and post-test counselling [HSOC0023062, page 10]. Was this idea presented to any member or representative of the Government? If so, what was the response?

174. I cannot recall but it would likely have been an idea raised at an Alliance meeting. I cannot recall any responses.

Q114: Please describe any and all efforts made by the Haemophilia Society to campaign or advocate for issues associated with vCJD and particularly consent.

175. I cannot recall specific details, GRO-A having also received batches later discovered to have potential impact. I cannot recall a specific campaign but I reference the letter and fact sheet that was issued in 2004 (**Exhibit WITN5684003**).

Q115: Did the Haemophilia Society engage in any campaigning efforts regarding vCJD testing or other issues experienced by members in relation to vCJD?

176. I unfortunately cannot recall any details on testing. I can only refer to the fact sheet of 2004 (**Exhibit WITN5684003**) but unable to recall any other specific campaigning issues on vCJD.

Q116: The 2011 Spring issue of HQ [HSOC0023062] states that the Haemophilia Society was "working closely" with the Department of Health. Please provide as much detail as possible regarding any communication and meetings between the Haemophilia Society and the Department of Health on vCJD? If any assurances were made, please also provide details of them.

177. I cannot recall any details.

8.1 Recombinant

Q117: Please detail what the position of the Haemophilia Society was on recombinant products during your tenure?

178. The HS was consistent that it should be for ALL.

Q118: Did the Haemophilia Society engage in any campaigning efforts to try to obtain widespread treatment with recombinant products?

179. I unfortunately cannot recall but I believe the HS would have lobbied for this with DoH and UKHCDO. This would have been because of the historical issues with contaminated blood and HIV/HepC and later the emergence of vCJD. Generally, I think it was felt that everyone should have access to safe clotting products, despite that some were already infected with one or both viruses.

Q119: Did the Society make any Government representatives aware of the Society's position? If so, what was their response? Did the Society rely on any such response? If so, how?

180. I am sure we would have – but unfortunately, I cannot recall any further detail.

Q120: Did the Government provide the Society with any reassurances about recombinant products such as those mentioned in HSOC0023077, page 2.

181. I cannot recall and unaware at this length of time passed what the outcome of the tendering process was. There may be letters available from the Society that would reference or record any responses.

Section 9: Other Issues

Q121: 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?

182. I do not believe any documents were purposely destroyed by the HS. In the history of the HS, its headquarters has moved locations in the region of 5 to 7 times. It is therefore conceivable that document management was not as robust as it could have been and documents may well have been thinned out or destroyed unintentionally since the Society was founded but this is speculation.

Q122: 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.

183. I cannot think of any other matters that would be relevant to the Inquiry and its Terms of Reference. The answers provided above are to the best of my knowledge and recollections. During my tenure, the HS was not wholly focussed on contaminated blood issues but was trying to deliver services to a broad church of membership, some of whom had not been touched, thankfully, by the contaminated blood issues.

184. The HS is a small charity with what I still believe to be limited resources trying to deliver multiple streams of support to its membership. However, it is my belief that all of the current and former Trustees and staff have only ever wanted the best outcomes for all those affected by bleeding disorders. I think the HS has always held the belief that the impact of infected blood on current and, sadly now so many deceased infected individuals and their families should be heard and acknowledged. This public inquiry into the worst disaster in the history of the NHS is long overdue and sadly too late for so many. I hope when it concludes that it will bring closure and positive outcomes for all of those who have been impacted. It both saddens and angers me that many friends and acquaintances that I have met over the 30 years I have been involved with the Haemophilia community, including former Trustees will not be here for that day.

Statement of Truth

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

Signed **GRO-C**

Dated : 30 July 2021