Witness Name: Babs Evans
Statement No: WITN5593001
Exhibits: WITN5593002-WITN5593005
Dated: 31 May 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BABS EVANS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 April 2021.

I, Babs Evans, will say as follows: -

Section 1: Introduction

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

1. My official name is Barbara Evans, but I am known as Babs in my personal and professional life and was known as Babs Evans when I worked at the Haemophilia Society.

2. DOB: GRO-C 1961

3. Address: GRO-C London, GRO-C

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.

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.

Pre-Haemophilia Society employment (before 2000) [WITN5593002]

4. My original career was as a Graphic Designer, working with advertising and design agencies, some specialising in pharmaceutical advertising (no campaigns or resources were related to haemophilia or HIV treatment), in the UK and Kenya. I also worked as a self-employed Graphic Designer in London for a number of years until 1991.

5. In 1991, the recession had seriously impacted my ability to find work. Alongside this, I had been caring for my partner who was a wheelchair user and had become involved in supporting others with benefit applications etc. I decided to change career and went to work for the Jewish Blind and Disabled Society as a sheltered housing manager. I have worked in the not-for-profit sector since then. The other two roles I had before joining the Haemophilia Society were as a Housing Support Officer, with Kensington and Chelsea TMO and then with Hammersmith and Fulham Council.

Post Haemophilia Society employment (after 2003)

6. After leaving the Haemophilia Society in 2003, I worked for the National AIDS Trust where, in 2004, I organised the largest residential conference of people living with HIV. I then took a role at Macmillan Cancer Support, developing a UK-wide self management programme delivered by and for people living with cancer. This was building on the work I had done both at the Haemophilia Society and as a volunteer tutor on self-management programmes to deliver more tailored programmes, including one for people with HIV.

7. Since then, I have worked on funding programmes and for organisations, including The Elton John AIDS Foundation, where I developed the UK Strategy and funding programme, as well as managed a portfolio of grants in the UK and internationally; MBARC Research and Consultancy, where I led the design and implementation of a £2.4m HIV Prevention England funding programme on behalf of the Department of Health; The MTV Staying Alive Foundation (HIV specific funding mainly international); Tesco Charity Partnership (with Diabetes UK and British Heart Foundation); BBC Children in Need.

8. Since April 2018 I have been employed as Head of Grants at The Henry Smith Charity, which is an endowed Foundation. I am a member of the Senior Management Team and Head of a Department. I am responsible for the Main Grants programme, awarding approximately £30m in grant funding to charities throughout the UK per year.

Personal circumstances and voluntary work

9. In 1994 I went to my local blood donor centre and gave blood. A few weeks later I received a letter to say that there was something unusual about my blood and that I should make an appointment at the centre. I was told that I had the AIDS virus. When discussing when I might have been infected, we identified that I had must have been infected at the end of 1987. It was explained that as I had been infected six years prior, it was likely that I would die of AIDS within two years.

10. I wasn't given any relevant information but referred to a local hospital. I discovered that there was an organisation called Positively Women (now Positively UK) and I was able to attend support groups and meet other women who were living with HIV. They were fantastic role models and I learnt so much from them. They also held information sessions about different topics, including treatment options, relationship issues, preparing for death and creating memory boxes. I met and became friends with women who died but others who, like me survived and I am still in contact with.

11. I also attended a newly diagnosed group at the London Lighthouse and developed a close friendship with two gay men from the group. One died, but the other is still my closest friend and like a family member.

12. Positively Women was promoted to me as an organisation run by and for women living with HIV, however although all the peer support workers were women living with HIV, they were under-represented at the senior level of the organisation and on the board. I got more involved, was co-opted as a trustee and was asked to be Chair, which I did from 1995-7. In taking on this role I decided to be public about my HIV status. Through all the support I received I felt able to do this, my family and partner knew my status by then, and I felt it would not have been acceptable to be Chair without being able to speak openly about my own status. I did TV interviews, magazine features and featured in HIV sector publications. This was a significant

development as when I was first diagnosed, I was very scared about anyone finding out, especially my employers, and even intercepted the postman every day in case any written material got delivered to someone else in error.

13. Before I went to work at the Haemophilia Society, I only came into contact with two people connected to haemophilia and HIV. At the time I served on the board of Positively Women, Clair Walton was also a trustee and I learnt about her personal circumstances. In 1995 (I think) I met Robert James at a conference of people with HIV in Bournemouth and I learnt a lot about haemophilia and HIV from him. Before taking the job at the Haemophilia Society, despite being heavily involved in the AIDS sector and subscribing to almost every AIDS related publication I came across, I don't remember reading anything about haemophilia and HIV. It felt like a hidden community.

14. I was a member of the British HIV Association during the time I was employed at the Haemophilia Society (and in subsequent years related to my roles).

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.

15. I have not provided any evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products.

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

Q5. The Inquiry is aware that you served as a HIV/HCV Worker from 2000-2003 [HSOC0016593_008; DHSC0003033_005]. Please confirm and explain what your role and responsibilities were in relation to each position and how your role and responsibilities changed over time. If you held any other positions within the

Haemophilia Society, please set them out. You may be assisted by [HSOC0011164 (page 24-28)].

16. I was employed as HIV/HCV Worker at the Haemophilia Society from Monday 3 April 2000 to November 2003. My role was originally intended to provide information and support to people with HIV (through publications and the helpline) and to support the Hepatitis Worker.

17. When I started in post, there was no way of contacting people with haemophilia and HIV/HCV. The Haemophilia Society didn't have a contact database of people living with HIV/HCV, and the only way people got information directly from the Haemophilia Society was via the quarterly hard copy of the newsletter, which individuals had to subscribe to and pay for. This was at a time when there was not widespread use of home computers or personal email addresses, and before social media.

18. The only way I could get in touch with anyone at the start was by other colleagues advising me of people I could speak to. I spent the first few weeks of my role travelling around the UK meeting up with men with haemophilia and HIV/HCV and hearing about their experiences with the Haemophilia Society, Macfarlane Trust and Birchgrove. I learnt about the challenges people had getting extra financial support from the Macfarlane Trust, with some describing it as like a 'parental relationship', having to ask for money all the time, and having to frequently visit their Haemophilia Centre to get a health professional or social worker to endorse their request.

19. I also asked whether people attended support groups run by HIV organisations in their area and found that very few did, some had tried but they had not met their needs, and that there was an expectation that the Haemophilia Society and Macfarlane Trust should be meeting their information and psycho-social needs, with disappointment that this had not been happening. I found out that some people were not on the most up to-date and recommended HIV medication regimes.

20. I persuaded GRO-B to help me with the work and he became a volunteer at the office in order to do this. It was a big change at the Haemophilia Society as volunteers had mainly been used to raise money, or stuff envelopes and new policies and procedures had to be developed. I also worked with Andrew Evans, who had already been involved in organising the young men's weekend in Blackpool before I joined.

21. It was clear that I had a lot of trust to build up for people to feel able to contact me for the information and support I was supposed to be providing. Adding to the complications were that in order to let people know I was even in post, apart from those that may subscribe to the Haemophilia Society quarterly newsletter, there were gatekeepers to reaching people with haemophilia and HIV/HCV.

22. The Macfarlane Trust was the organisation that had the contact details of everyone who had been infected with HIV/HCV from contaminated blood products, so it was important that I built a relationship with staff working for the Trust. It was also clear that I had an advocacy role with them too. Haemophilia Centres were also a point of contact for people with haemophilia and HIV/HCV, however I discovered that some centres did not want to display anything to do with HIV in their centres. This made it challenging to disseminate information.

23. Compared to my own experience of getting support, getting up to date treatment information and having positive role models to learn from, I felt that men with haemophilia and HIV/HCV and their families were a neglected community, having little or no opportunity to interact with each other in a positive way, and as a community, had fallen through a significant gap. Generic HIV organisations were not meeting their needs and it was clear to me that I had the opportunity to try and improve the support people received from the Haemophilia Society. I gradually built-up contacts and as more people started to get, and share, personal email addresses, I produced a monthly information email which I circulated. This was at a time when guidance and treatment options in relation to HIV/HCV were developing at a pace.

24. I often describe my role as HIV/HCV Worker at the Haemophilia Society as being a 'one woman AIDS support organisation'. I contributed to HIV policy work with the National AIDS Trust, I attended the British HIV Association conferences and treatment updates from NAM, and translated what I learnt into easy to understand treatment information and I did advocacy work.

25. I organised events for health professionals such as in May 2001 HIV and HCV Co infection: Current developments in treatment and care, funded by The Department of Health, Roche, Schering Plough and the John Ellerman Foundation. I also organised a two-day conference for health professionals and the HIV sector in November 2003: HIV and hepatitis co-infection which was sponsored by Roche Products Ltd, Schering

Plough, Abbott Laboratories Limited, Bristol Myers Squibb, Gilead [WITN5593003;WITN5593004] .

26. I organised a number of co-infection seminars around the UK for people with haemophilia and HIV/HCV and residential support and information events for people with haemophilia and HIV/HCV and their families. I produced a ground-breaking resource for gay men with haemophilia and I ran a helpline. Through all of this, I made sure that I actively involved men with haemophilia and HIV/HCV and their partners, adopting best practice in co-production.

27. I left the Haemophilia Society as my role was to be changed to a more generic one. It was not what I wanted to do, it wasn't what I was originally employed to do, and it was not the best use of my skills, experience and knowledge, built up over a considerable time. I had become known for the specialist HIV/HCV co-infection work and I believe I was the first person employed in any HIV or other charitable organisation that had this remit. An example of the standing of this role and how I was able to call on expertise, is in the May/June 2001 issue of Positively Women's newsletter. I started a regular column about co-infection issues and interviewed Dr Janice Main, Senior Lecturer in Infectious Diseases and General Medicine at St Mary's Hospital.

28. I personally felt that there was so much still to do with and for people with haemophilia and HIV/HCV and their families, and that the case for my specialist role was still justified at the time these changes were implemented.

29. I read the Haemophilia Society Report to The Macfarlane Trust Partnership Group dated 8 December 2003. This was produced after I left the Haemophilia Society and describes the reasons the changes were made and the plans going forward. I had not seen this document before, and I note that the Haemophilia Society stated that one of the reasons was pressure on resources, and that by working with the Macfarlane Trust and Birchgrove 'we can jointly address the needs of co-infected people'. I think it is important to note that due to people dying and increasing ill-health, Birchgrove as a group had limited capacity.

30. I think that it had been a very positive move to appoint someone with the title HIV/HCV Worker as a very public commitment to the community of people living with haemophilia and HIV/HCV and their families. In changing the Hepatitis Worker role to a more generic title and not replacing the HIV/HCV Worker, this may have sent a

negative message to the community affected.

Q6. When you joined the Society, what were the objectives and functions of the Society? If these changed over time, please detail when and why.

Q7. Please describe how the organisation was structured, including the governance arrangements and the day to day management and running of the Society. Please set out the line management arrangements of staff including who your line manager was and the nature and extent of their management of you and oversight of your work. If this changed over the period of your tenure, please out those changes.

31. I joined the Society in April 2000. I can't remember what the official objectives of the Society were at that time but soon after I joined, an Operational Plan was developed, which was finalised in December 2000.

32. At the time I was working for the Haemophilia Society, Karin Pappenheim was the Chief Executive and most people reported to her, including myself and Lucy McGrath, Hepatitis Worker (and later John Morris), Talia Barry, Children and Families Worker, Joan Doyle and Ruth Taylor, Information and Advice Workers, Juliet Harris, Fundraising and Marketing Officer, Stephen Bowden, Finance Officer and Sue Rocks Personal Assistant to the Chief Executive. I think Tom Bradley, Communications Officer, reported to Sue Rocks and I think Helen Courtney, Services Administrator reported to Joan Doyle, but I'm not 100% sure about this.

33. Karin remained my manager throughout the time I was employed. I can't remember how regular my 1-1s were. When I started developing the role and achieving some success, I had quite a lot of autonomy, as long as there was funding in place for me to do what I felt the community needed. I was greatly supported in this by Juliet Harris, and we worked on some successful bids towards HIV specific work. I also worked closely with Lucy McGrath and we produced a booklet, *Hepatitis C – meeting the challenge,* along with people affected, which was highly commended in the healthy living category of the British Medical Association 2002 Patient Information Award.

34. The Chair at the time was Chris Hodgson. I can't remember who the other board members were at the time. I don't remember attending any board meetings. I do remember I was sometimes asked to produce information for Karin for the papers, but I can't remember any specifics of that.

3.1 Sub-committees, task groups and advisory bodies

Q8. Please list all the different Society sub-committees, task groups and advisory bodies that you were involved in and describe the purpose, functions and responsibilities of each committee, task group and advisory body. In your answer, please include a description of the following:

(a)Macfarlane Trust Partnership Group [MACF0000088_023]
(b)The Haemophilia Alliance [MACF0000088_021]

Macfarlane Trust Partnership Group

35. Along with a trustee of The Haemophilia Society, I was a member of the Partnership Group during the time I was employed at the Haemophilia Society (2000-2003). It is my understanding that the Partnership Group was formed by the Macfarlane Trust as a way to involve relevant stakeholders, including registrants of the trust, The Haemophilia Society, The Haemophilia Alliance, The UK Haemophilia Centre Directors Organisation (UKHCDO) and Birchgrove to be consulted on policy issues in relation to the trust. This is from my recollection and reviewing meeting notes, rather than a formal document outlining the purpose, functions and responsibilities of the Partnership Group, which I have not seen and can't remember ever seeing.

The Haemophilia Alliance

36. The Haemophilia Society was a member of the Haemophilia Alliance, but I can't remember attending any meetings. I think it was probably Karin that represented the Haemophilia Society and then gave us updates as a staff team.

Q9. Please outline the relationship between the Haemophilia Society (including the hepatitis task group) and the Manor House Group. Please set out any differences or disagreements in opinion, approach and/or actions taken by the two entities.

Hepatitis task group and the Manor House Group

37. My colleague Lucy McGrath, Hepatitis Worker (and later John Morris), was the person who would have held any relationships with the hepatitis task group and the

Manor House Group. I was not involved in these groups and I can't remember attending any meetings.

Q10. Please outline the relationship between the Haemophilia Society (including the hepatitis task group) and the Birchgrove Group. Please set out any differences or disagreements in opinion, approach and/or actions taken by the two entities.

Birchgrove Group

38. The Birchgrove Group was a self-help and support group of men living with haemophilia and HIV/HCV run entirely on a voluntary basis. It is my understanding that years before I joined the Haemophilia Society in 2003, the group had been quite active, produced a regular newsletter and organised some events. However key members of the group had died, and others were not in good health and the activities had reduced. I think that the Haemophilia Society provided some financial support to the group at one time, but I am not sure how much or when.

39. When I joined the Haemophilia Society, I got the impression that there had been a difficult relationship with some members of the Birchgrove Group, and I think some staff members found working with some of the group members quite challenging. Some members of the Birchgrove Group wanted the Haemophilia Society to be more vocal about the impact of contaminated blood and to campaign more for a public enquiry. Some of the articles written in the Birchgrove magazine were critical of the Haemophilia Society's support (or perceived lack of support) to men with haemophilia and HIV/HCV.

40. I don't know what the relationship was between the Birchgrove Group and the hepatitis task group.

Section 4: Communication and Dissemination of Information by the Society

4.1 Knowledge of Risk

Q11. When you first joined the Society:

(a)What did you know and understand about the risks of the transmission of HCV from blood and blood products? What were the sources of your knowledge? How did your

knowledge and understanding develop over time?

(b)What did you know and understand about the health implications of HCV infection? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

(c)What did you know and understand about the prevalence of HCV infection amongst haemophiliacs? What were your sources of their knowledge? How did your knowledge and understanding develop over time?

41. When I joined the Haemophilia Society I knew about the risks of transmission of HCV from blood and blood products as I had been involved in the HIV sector for a number of years and HIV/HCV co-infection was becoming an increasing concern, particularly amongst injecting drug-using communities.

42. As part of my induction, I met people living with haemophilia and HIV/HCV as well as people with haemophilia and HCV who were able to tell me about their personal experiences. I had an extensive induction with Lucy McGrath, Hepatitis Worker who signposted me to relevant papers and journals and I read about the history of contaminated blood products.

43. I developed my knowledge and understanding of the impact and treatment of HCV through attending both HIV and HCV medical conferences and events, talking to specialists and reading research papers. I also carried out my own research into the attitudes and experience of people living with haemophilia and HIV with regard to HCV treatment, which I presented at a conference (I can't remember which one or when).

44. I got the data about HCV infection amongst people with haemophilia from national data, which I think was published by the UKHCDO.

Q12. When and in what circumstances did you become aware of any risks of transmission of vCJD associated with the use of blood and blood products? What were your sources of their knowledge? How did your knowledge and understanding develop over time?

Q13. During your employment, what actions did the Society take in relation to the risk of transmission of vCJD via blood products, if any? What representations (if any) were made to Haemophilia Society members, the Government or the UKHCDO in relation to these risks?

45. In 2002, the Haemophilia Society took part in a consultation held by the Department of Health's (DH) vCJD incident panel. It identified the need for more research into the possible risk that vCJD could be transmitted through blood or blood products. I was aware of this work and the fact that the DH funded a five-year study with UKHCDO as it was featured in the Haemophilia Society's HQ Issue 4 Winter 2002. I know some fact sheets were produced about vCJD and the risks of transmission, but I wasn't involved in their production and I can't remember when they were produced.

4.2 Publications

Q14. Please identify the members, groups and/or committees of the Society responsible for editing and selecting material for the Society publications during your tenure.

46. For the work I was involved in, including joint work with Lucy McGrath, Hepatitis worker, all publications involved people affected by the issue (examples were *Hepatitis C – meeting the Challenge, You don't have to be straight to take Factor 8, HIV and HCV Co-infection Current developments in treatment and care)* and were fact checked by the appropriate medical specialists. I can't remember the names of the health professionals we involved but they were listed in the publications. They were sent the draft copy to comment on from a medical perspective to make sure that medical information was correct. If they highlighted anything that was inaccurate, we always changed it. Occasionally health professionals suggested amendments related to style and tone, rather than factual medical information. This was not their remit and changes were rarely made in these instances.

Q15. Please detail the publications that the Society sent out to its membership during your tenure. Please describe the frequency with which each type of publication was disseminated and whether they were all sent out to all members of the Society. If this changed over time please detail when and why. The Inquiry is aware of:

(a) The Bulletin [HSOC0023033];
(b) C Issues [HSOC0016622];

(c)Haemophilia Quarterly [HSOC0005802].

Q16. To what extent, if any, did haemophilia centre directors and members of the Medical Advisory Panel assist in proposing and/or editing and/or selecting material for the Haemophilia Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

47. During the time I worked at the Haemophilia Society, the Society distributed HQ quarterly to members (I think it was previously called The Bulletin). I think members of the Medical Advisory group fact checked medical information but I don't remember who the members of this group were, what the process was or whether there were any instances where their advice wasn't taken. I do remember conversations about whether all issues should be sent to all subscribers, regardless of whether they paid or not, or whether non-paying members or subscribers should get fewer issues. Unfortunately, I can't remember what the outcome of these discussions were.

48. I think C issues was quarterly and went out with HQ, but I think this was sent to anyone who expressed an interest in receiving information about hepatitis C.

Q17. To what extent, if any, did representatives of pharmaceutical companies assist in proposing and/or editing and/or selecting material for the Society's publications? If you have already answered this question in other sections of your response, please identify the paragraph number(s).

49. To my knowledge, representatives of pharmaceutical companies did not assist in proposing and/or editing and/or selecting material for the Society's publications and there were strict guidelines about this.

4.3 Communication with members

Q18. Please describe your role, if any, in responding to direct inquiries from the Haemophilia Society's membership, including:

(a)How often you would receive inquiries;

(b)How members would raise inquiries, for example, by telephone or email;

(c) The general nature of those inquiries;

(d) Whether members raised inquiries of a medical nature;

(e) If so, what the Haemophilia Society's practice for responding to medical inquiries was.

50. I can't remember now how often I dealt with enquiries but I produced statistics about this for reporting so this information may be available from the Haemophilia Society. When I first started work at the Haemophilia Society, most enquiries were through the helpline as email was not widely used, however this changed over time and I had an increase in emails, especially as I built up my contacts of men with haemophilia and HIV/HCV.

51. I did sometimes take calls from people seeking benefits advice, which I passed on to the specialist advisors. I did the same with enquiries about haemophilia treatment in general in relation to children, as this was not an area I was confident in responding to.

52. Enquiries related to HIV/HCV were extremely varied. As mentioned, it was as if I was an AIDS helpline, so the nature of calls included issues with the Macfarlane Trust, psycho-social support, HIV treatment, HCV treatment, relationships etc.

53. One day I had a call from a man with haemophilia and HIV/HCV who told me he had '*had enough*' and was going to go into the woods and kill himself. He wouldn't tell me his name, or where he lived and there was no caller recognition on phones at that time. I spent a long time talking to him and at the end of the call I felt I had persuaded him to seek help. I will never know, and that call has stayed with me. It was an indication of the isolation, stigma and helplessness that people felt.

54. If enquiries were related to medical information, I was very clear that I could not give advice or tell people what to do. I signposted people to existing material that had been produced and fact checked by medical experts. This included for example BHIVA guidelines about treatment, the National AIDS Manual (NAM) website, fact sheets and booklets and Haemophilia factsheets and publications. The factsheets and booklets produced by the Haemophilia Society were fact checked by medical professionals (see paragraph 46). I can't remember the names of the health

professionals but usually there would be an acknowledgement of their involvement in the publication or at the end of the fact sheet. The BHIVA guidelines were produced by health professionals. The information about HIV that I distributed from NAM was respected, high-quality information and NAM had their own robust process of checking medical information. I sent information by post or email and also provided other telephone numbers and sources of support, depending on the issue.

Q19. Did the Haemophilia Society receive direct inquiries from the public or members who required advice with regard to the safety of blood products? If so, how were these queries handled? Who would respond? What resources (if any) did the Haemophilia Society rely on to enable a response? Please set out specifically, to the best of your knowledge, what advice and/or information the Society had and from whom that had been provided.

55. I can't remember getting any enquiries with regard to the safety of blood products, as my role was specific to HIV/HCV but if I had, I would signpost to the factsheets that we had and I can't remember now what they were called specifically.

Q20. Please detail any other activities that the Society conducted with the purpose of disseminating information to its members during your tenure. If this changed over time please detail when and why.

56. As mentioned previously, once I had an email contact list, I sent out email updates about matters related to HIV/HCV. I think I did this monthly.

Section 5: Relationship with the Government

5.1 Hepatitis C campaign

Q21. Please explain, giving as much detail as you are able:

(a) Your role and responsibilities (if any) in relation to the Society's campaign for compensation for haemophiliacs infected with HCV as a result of contaminated blood products;

(b)The role and responsibilities of the "Hepatitis Campaign Group" in relation to the

Society's campaign for compensation for haemophiliacs infected with HCV as a result of contaminated blood products?

(c)The aims of the campaign;

(d)Whether those aims changed;

(e)Who was responsible for the campaign;

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

(g)Any obstacles the Society faced in achieving those aims including, but not limited to, internal disagreements within the Society and its associated campaign groups, such as the Manor House Group;

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

(i)Whether the Society achieved its aims;

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

(k)If not, what the result of the campaign was;

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

57. I feel unable to comment about this section as I did not have any role or responsibilities in relation to the Society's campaign for compensation for haemophiliacs infected with HCV as a result of contaminated blood products.

Section 6: The Partnership Group

Q22. In answering the questions in this section you may be assisted by [MACF0000088_024; MACF0000088_023; MACF0000088_022; MACF0000088_021; MACF0000088_020; MACF0000088_018; MACF0000088_016; MACF0000088_015; MACF0000088_014; MACF0000009_195]

Q23. Please describe your role and responsibilities as a staff member at the Partnership Group ("PG"), including the dates you held that position.

Q24. Please describe the working relationship between yourself and the senior management of the Macfarlane Trust ("MFT"). Were there any difficulties? If so, what were they, how did they impact on the running of the MFT and how, if at all, were they resolved?

58. I was not involved in the previous strategy group or the 'old' partnership group so I can't comment on what the differences were.

59. I saw my role in attendance at these meetings as part of improving joint working with the Macfarlane Trust, ensuring that all stakeholders attending were kept updated about my work and any relevant significant developments related to HIV/HCV and advocating and feeding in any relevant themes and issues arising that had been brought to my attention as part of my role as HIV/HCV Worker.

60. I developed a working relationship with the senior management of the Macfarlane Trust. As described previously, I needed to do this as the Trust was the only organisation with all the contact details of people who could potentially benefit from the support and information I had been employed to provide.

Q25. What were the aims and objectives of the PG? Do you think the PG achieved those aims and objectives during the years you were a member? If not, why not, and what acted as a barrier to those objectives being achieved?

Q26. Please answer the following questions:

(a)How did you come to be involved in the PG?

(b)How many people were members of the PG?

(c)Who was the membership composed of, such as beneficiaries, trustees, or MFT staff?

(d)How did the PG interact with other organisations such as the Macfarlane Trust, the Haemophilia Alliance, and the Birchgrove Group?

(e)How frequently did the PG meet?

(f)Did you report to anyone at the Haemophilia Society? If so, who?

Q27. In a note of a meeting dated 6 June 2000 it was agreed to recommend to the Partnership Group to set up two working parties to meet the needs of affected people [MACF0000006_026]. What were the aims and objectives of these working parties? What was your role in these working parties? Who else was in these working parties? Please describe the work of these working parties. You may be assisted by [MACF0000088_023; MACF0000088_022]

Q28. What were the aims and objectives of the New Partnership Group and why was it formed? Did it exist at the same time as the original PG? You may wish to refer to the minutes of The New Partnership Group meeting held on 10 August 2000 [MACF0000088_023].

Q29. As far as you are aware, was it common for the MFT Board of Trustees and members of the PG to hold differing opinions? In particular, were there any disagreements in relation to financial management and the levels of reserve that were retained in the fund? If so, how were they resolved?

Q30. During your time with the PG, were there any issues between registrants of the MFT and those who were not registrant members? Please provide details of any specific circumstances you can recall or any issues on which there was disagreement.

Q31. Did the PG play any role in identifying new beneficiaries? If so – what steps did you take to identify new beneficiaries? How successful were they? Could more have been done?

61. I think the Partnership Group met two or three times a year and I reported back to Karin at the Haemophilia Society and disseminated notes and relevant issues arising to colleagues and at team meetings.

62. In order to involve all stakeholders in organising effective conferences and seminars that would create a safe place and meet the needs of men with haemophilia and HIV/HCV and their families, operational working groups were formed. I think I chaired these working groups, but it may have been someone else.

63. I can't remember much more about the Partnership Groups themselves and the interactions between individuals, but there are notes of meetings which clearly indicate some differences of opinions. I can't remember anything about identifying new beneficiaries.

Q32. As far as you are aware, what practical support or assistance was available to applicants to help them in making applications? Did many applicants take advantage of this assistance?

Q33. As far as you are aware, what steps did the MFT take to engage with and understand their beneficiary community?

Q34. What role, if any, did you play in assisting the MFT in determining the needs of the beneficiary community?

Q35. What was the relationship between the senior management/board of the Haemophilia SocietyMFT and the MFT beneficiary community? Could this have been improved in your view? What steps did you take to improve the relationships?

Q36. Please describe the role of the Haemophilia Society in supporting the residential weekends in partnership with MFT. You may be assisted by MACF0000080_049; HSOC0026815; MACF0000080_137

(a)How regularly were residential weekends or MFT events organised?

(b)What was the level of take-up among beneficiaries for these residential weekends?

(c)How did you become involved in organising residential weekends and events for

the Haemophilia Society or MFT? For how long were you responsible for organising such events?

(d)How did the events provide support for the beneficiary community?

(e)How were the residential weekends funded?

64. The MFT made some effort to engage with and understand their beneficiary community through conducting surveys of registrants. Through the conferences and events I organised, representatives of MFT, particularly the Chair, were able to attend and meet a wider group of people than were represented on the Partnership Group and hear their experiences. Also, by attending some of the sessions they learnt more about HIV-related issues and from the conference reports, issues that arose in the closed sessions.

65. The Haemophilia Society, through my role, supported the organisation of the residential weekends, providing additional staff resources to help with the administration of the event, funding, paying invoices etc. as well as providing information resources to display at the events.

66. When I joined the Haemophilia Society, funding for a Young People's Project had been obtained from the Elton John AIDS Foundation, The John Ellerman Trust and The Pilgrim Trust. The funding included the organisation of a residential event, building on one that had been held by my predecessor. I worked with Andrew Evans and we reviewed what worked well and what could be improved and organised two more residentials with the above funding. September 2000 was attended by 13 men and 8 partners, September 2001 was attended by 15 men and 12 partners.

67. It was clear that the young men had benefited from meeting and learning from older men, and partners in particular wanted to meet other partners, especially those that had children. This is why we went on to organise *Something for the weekend* in 2002, which was open to all ages and all registrants of the Macfarlane Trust who were living with HIV, as well as their partners. 65 people attended. This was funded by Birchgrove, Birchgrove North, Cambridge and District Group, GMTV Get up and Give Appeal, Macfarlane Trust and Roche Products Ltd [WITN5593005].

68. Although relatively speaking, numbers were relatively small, I feel that momentum

was building and there was potential to build trust and increase the reach. As I mentioned in my own experience, I was fortunate to be able to access support and meet others going through similar circumstances, which was a great help.

69. For a lot of men living with HIV/HCV and their families, often HIV was never spoken about. For some of the younger men diagnosed as children, once they were told they had AIDS (often as teenagers) they were informed they would die and told not to have sex and then it was never spoken of again. The residential events were an opportunity for people to feel *'normal'* (for the want of a better word). To be with people who were living with the same or similar challenges, to be able to speak openly about HIV/HCV, to discuss issues they couldn't talk about with friends or other family members and to find a way to manage their situation better.

Q37. Do you think there was adequate funding available for residential weekends, including for the Bereavement Project? Why do you think the MFT was unable to sponsor more of these events? You may wish to refer to the minutes of the Partnership Group meeting held on 7 November 2002 [MACF0000088_014].

70. The weekends I organised as part of my role at the Haemophilia Society could only go ahead if we were able to get funding. Other funding priorities for the organisation had to be considered and sometimes we had to rely on confirmation of the funding contribution from the Macfarlane Trust before we could start to plan. It was difficult to get funding from Trusts and Foundations as the unit cost was high and evaluation and demonstration of the longer-term impact was really important, and took a lot of time and effort.

71. As mentioned before, I feel that men living with HIV/HCV, their families and the bereaved fell through the gaps in terms of supporting their psycho-social needs and because of the nature of the widespread infection through contaminated blood, were located around the UK. This made it almost impossible to offer any local support, and potentially less likely that people would access it if they were worried about others finding out about their situation. Residential events to bring people living throughout the UK seemed to be the best solution.

72. Obviously, this means a much higher cost base than attending a local event or support group and as mentioned funding was an issue. There was also a questioning about who should fund this type of work, with the Macfarlane Trust feeling that the

Haemophilia Society had more resources to do so (although as indicated, this was reliant on being able to get grants from funders willing to fund HIV related work and for relatively small numbers of people).

73. There were also often discussion and debates about whether it was within the remit of the Macfarlane Trust to provide psycho-social support and some people involved in the Haemophilia Society felt that it was their remit and not the Haemophilia Society's, especially in relation to those who had been bereaved. Personally, I feel that this did sit with the Macfarlane Trust as those that were bereaved did not have haemophilia, and no longer a reason to be a member of the Haemophilia Society if they had been before their partner died.

Q38. Do you consider that the PG was well run? Do you consider that it achieved its aims and objectives? Were there difficulties or shortcomings in the way in which the PG operated or in its dealings with beneficiaries and applicants for assistance?

74. I don't feel able to comment on whether the Partnership achieved its aims and objectives as I am not clear on exactly what those were. I think it was an opportunity to involve stakeholders and there was progress and positive change in some areas. As I was only involved for three years, I can't comment on whether the Partnership Group had any longer-term impact on the policies and practices of the Macfarlane Trust or the other organisations involved.

Q39. Do you consider that the Haemophilia Society was well run? Do you consider that it achieved its aims and objectives? Were there difficulties or shortcomings in the way in which the MFT operated or in its dealings with beneficiaries and applicants for assistance?

75. At the time I worked for the Haemophilia Society, I think it was reasonably well run, however there was always a conflict between what some members wanted (in relation to campaigning for a public enquiry etc.), and the needs of other members who had not been impacted by contaminated blood.

Section 7: Other Issues

Q40. To the best of your knowledge, at any point, did Society staff and committee members purposefully or unintentionally destroy documents relevant to the Terms of Reference of the Infected Blood Inquiry?

Q41. 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.

76. During the period I worked at the Haemophilia Society (2000-2003) I don't think any documents relevant to the Terms of Reference of the Infected Blood Inquiry were purposefully destroyed. However, I remember that during this time there was a big clear out of paperwork in the office, so it is possible that documents have been destroyed as their future relevance to the Infected Blood Inquiry may not have been appreciated at the time.

Statement of Truth

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

Signed: **GRO-C**

Dated: 31 May 2021