Witness Name: KATHERINE VICTORIA BURT
Statement No.: Second WITN6392268
Exhibits: WITN6392269 – WITN6392280
Dated: 25 August 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KATHERINE VICTORIA BURT

I provide this statement on behalf of The Haemophilia Society in response to the requests under Rule 9 of the Inquiry Rules 2006 dated 10 May 2021, 18 May 2021, 4 June 2021, 20 July 2022 and 23 August 2022.

I, Katherine Victoria Burt, will say as follows: -

Section 1: Introduction

1. My name is Katherine Victoria Burt, and am known as Kate. I am the current Chief Executive of The Haemophilia Society ("The Society") whose registered address is 52B Borough High Street, London, SE1 1XN. My date of birth is 7 November 1965. I have held the position of Chief Executive of The Society since 5 October 2020. All references hereafter to "The Society" are to The Haemophilia Society unless otherwise indicated. I am authorised by The Society to make this statement.

2. This is my second statement to this Inquiry. My first statement to the Infected Blood Inquiry ("the Inquiry") is dated 9 August 2022 [WITN6392001] ("my first statement to the Inquiry") and I make reference to it throughout this statement.

3. The Society has been the subject of various criticisms set out in the written statements of W1122, W5739, W1055, W1056, W1210, W1791, W3988, W4120 and W3261.In this statement, I address the matters that this Inquiry has requested that I respond to in the following letters from the Inquiry regarding these criticisms:

   a. Rule 9 letter dated 10 May 2021 in relation to criticisms made by W1122;
   b. Rule 9 letter dated 18 May 2021 in relation to criticisms made by W5739;
   c. Rule 9 letter dated 4 June 2021 in relation to criticisms made by W1055, W1056, W1210, W1791 and W3988;
   d. Rule 9 letter dated 20 July 2022 in relation to criticisms made by W4120;
   e. Rule 9 letter dated 23 August 2022 in relation to criticisms made by W3261.

4. The criticisms referred to above relate to five broad topics, including:
   a. Topic 1: Historical focus and objectives of The Society;
   b. Topic 2: The Society's advocacy and campaigning in relation to HIV, Hepatitis C and contaminated blood products;
   c. Topic 3: The Society and the Birchgrove Group;
   d. Topic 4: The Society and the UKHCDO; and
   e. Topic 5: The Society and the pharmaceutical industry.

5. In this statement, I refer to criticisms made by W1122, W5739, W1055, W1056, W1210, W1791, W3988, W4120 and W3261 under the headings listed in the paragraph above. As the criticisms relate to a time before I joined The Society, I have mainly relied on documents held by The Society (and provided to the Inquiry) to prepare this statement. I have done my best to provide comprehensive and accurate responses to the criticisms, based on my own knowledge, the knowledge of some existing Society trustees and the available documents. Based on this material, I set out a chronological account that highlights the various campaigns, activities and actions undertaken by The Society in relation to the abovementioned topics over the period from 1981 to 2015. This statement is not an exhaustive chronological account of all of The Society's actions campaigns, activities and actions undertaken over the period relevant to the Inquiry's terms of reference, it has been prepared in order to respond to the specific criticisms made.

6. I have attended many of the Inquiry hearings in person and listened to evidence remotely. I have read a number of statements as well as documents. Since commencing my role with The Society, I have met with many individuals infected and

affected by contaminated blood and been kept apprised of the evidence and read summaries of the evidence. I have also worked with the three other Haemophilia Societies in the United Kingdom in relation to this important work. I consider it a crucial part of my role to understand what people with bleeding disorders have experienced in the past in order to best assist them in the future. As much as anyone can who is not directly infected or affected, I think I have a reasonable insight into where those witnesses to whom I am asked to respond are coming from.

Professional qualifications and current role at The Society

7. Prior to joining The Society in October 2020, I was an Executive Director at Leonard Cheshire, a global disability charity, leading their marketing and fundraising work. I have also worked as:
   a. a director at Police Now, recruiting individuals to be police officers;
   b. as the chief operating officer at Greenhouse Sports, a charity working with young people in inner cities helping them to release their potential through sport; and
   c. from 2012 to 2014, I was the chief executive of British Rowing;
   d. as well as a number of other roles, including the Director of Business Development at The Prince's Trust.

8. As Chief Executive of The Society, reporting to the Board of Trustees, I am responsible for setting the strategic direction of the organisation, ensuring we have the highest standards of governance and have diverse and sustainable income streams with the objective of providing support to the bleeding disorder community in the UK. My focus is to position the UK as a leading country in the global bleeding disorders community through engagement with the European Haemophilia Consortium ("EHC"), the World Federation of Hemophilia ("WFH") and other haemophilia societies around the globe. We continue to advocate for consistent and high standards of care across the UK through engagement with Haemophilia Centres and the APPG. And we develop and provide education on innovations in treatment, such as Gene Therapy, which is in clinical trials and a current focus for many with a bleeding disorder.

Topic 1: Historical focus and objectives of The Society

9. The Society is the only UK-wide charity for all those affected by a genetic bleeding disorder. It was established in 1950 to help people with genetic bleeding disorders to lead fulfilling lives, make informed choices and to support and inspire others. Our vision is for anyone affected by a genetic bleeding disorder to have the opportunity to fulfil their ambitions and potential, regardless of their disorder, and to know that the companionship of others with a bleeding disorder who understand its demands, is always available to them. To my mind, this is a contemporary framing of what, decades ago, The Society termed “fellowship”. Our mission is to inform; advocate; and empower. Our values were updated in November 2021 to be:

Empowering	Informative and supportive – We help our members throughout their lives
Compassionate	Approachable and inclusive – We put our members at the heart of everything we do
Resilient	Inspiring and engaging – We deliver positive impacts for our members and the community

10. We aim to ensure that everyone affected by a bleeding disorder:
    a. Has equality of opportunity;
    b. Has the opportunity to connect with others in the community, should they so choose; and
    c. Has the knowledge to feel empowered.

We do this by raising awareness about bleeding disorders; providing information and support throughout members’ lives; and influencing and advocating for the community on policy and access to treatment.

11. In this section, I refer to documents and evidence given to this Inquiry about the historical focus and objectives of The Society, before addressing a number of criticisms made by witnesses about the ways in which they believe The Society’s focus has shifted over time. For further background about the purpose and functions of The Society, both currently and historically, please refer to section 1, question 3 in my first statement to the Inquiry [WITN6392001].

12. Information about the purpose and function of The Society can be found at the beginning of each of The Society's annual reports. The annual reports dating from 2010 to 2021 are publicly available on The Society's website. These and earlier annual reports, where available, are exhibited to my first statement to the Inquiry [WITN6392001] at Exhibits WITN6392009 to WITN6392058 and WITN6392143.

13. The Society's annual report for the year ended 31 December 1966 (Exhibit WITN6392269) states its purpose as follows:

> *"The Haemophilia Society*
>
> *… is the nationwide voluntary organisation founded to provide a fellowship for haemophiliacs and those concerned with their health and welfare.*
>
> *… safeguards the social and economic interests of haemophiliacs and promotes the study of the causes and treatment of haemophilia and similar conditions."*

14. This purpose has been expanded over the years. A Society publication dating back to December 1981 makes reference to the aims and objectives of The Society based on a talk provided by a member of The Society's Executive Committee, Ken Milne, on 15 March 1981 (Exhibit DHSC0041295_049). On page 12 of that document, The Society's objectives are listed as:

> a) *To provide a fellowship for sufferers from Haemophilia and allied conditions, their families and those concerned with their health and welfare;*
> *b) To safeguard social and economic interests of such sufferers*
> *c) To promote the study of the cause and treatment of haemophilia and allied conditions;*
> *d) To gather and publish information useful to sufferers and the general public.*
> *e) To co-operate with the medical and allied professions for the furtherance of the objects of the Society;*
> *f) To co-operate with any other Societies or bodies having similar aims;*
> *g) To provide financial help where necessary and practicable;*
> *h) To do all other things which may legally be done in the furtherance of the Society's objects.*

15. David Watters refers to these objectives at paragraph 10 of his witness statement dated 18 February 2021 [WITN3429001]. David was the former Coordinator (later General Secretary) of The Society. He was employed by The Society between 1981 and 1994. He states that during his tenure, The Society *"was always there to provide for and promote the best interests of people with Haemophilia, and that didn't change during my employment. Even though we had to devote a lot of resources to HIV, AIDS and Hepatitis, the core activity was always representing the best interests of people with Haemophilia."*

16. The Society's annual report from 1985 (Exhibit WITN6392270) explains:

> *The Haemophilia Society was established in 1950 and was incorporated as a Company Limited by guarantee on 21st October 1983.*
>
> *The aims of the Society are:*
>
> *(a) To promote research into and the study of the causes diagnosis and treatment of haemophilia and all related blood disorders, including (but without prejudice nevertheless to the generality of the foregoing) research into and the development of processes, techniques and drugs for the cure, prevention and/or control of all such disorders, and publish the useful results of such research, and*
> *(b) To provide or assist in the provision of medical, surgical and pharmaceutical care and treatment together with advice and aid (both financial and in kind) for sufferers from haemophilia and all related disorders who are in need.*
>
> *In practice the Society operates at two levels — first of all that of providing support, friendship, advice and information to people with haemophilia — and those involved in their care. This is achieved through various publications, including The Bulletin, and by encouraging, for example, the formation of professional groups for nurses and social workers as well as local groups of members. Secondly, the Society seeks to encourage and support research into- the condition; since the Society was formed more than £450,000 has been collected for research and this has contributed greatly to the advances in treatment and care which benefit so many today.*

> *In recent years, we have recorded the steady growth which has taken place in the Society's activities and membership and the way in which the administration has been improved to deal more efficiently with the increasing requests for information and practical support.*

17. Peter Wetherell who was the Local Chairman of the Cambridge branch of The Society in 1981, and an Executive Committee Member of The Society from 1983 to 1990 states at paragraph 7 of his statement dated 9 April 2021 [WITN3912001] that The Society's objectives and functions when he joined were *"broadly to promote and protect the interests and well-being of haemophiliacs, their families and carers and the overriding objective was to seek improvements in care and treatment. To this end the objectives were to provide fellowship, raise funds to support local centres and the Haemophilia Society nationally, and to encourage research into improved and safer blood products."*

18. Andy Cowe, whose mother joined The Society when he was diagnosed with haemophilia in approximately 1953 to 1954 and who later went on to become a part of the Scottish Group Committee of The Society and a member of the Executive Committee until 1997 states at paragraphs 9 and 11 of his witness statement dated 28 April 2021 [WITN3647001] that The Society *"was about providing information and support to people with haemophilia and their families, and representing their interests to the medical profession… As to how the objectives and functions of the Society changed over time, I do not think the fundamental objectives changed over time, but clearly, the priorities changed to meet the needs at any particular time."*

19. Minutes of an Executive Committee meeting on 4 to 5 October 1991 (Exhibit HSOC0010387) record Mr Cowe listing the issues that were most important to The Society at the time:

> *Ms Luyster, while expressing admiration at how much the Society had achieved, asked, for clarity of purpose, where the main focus lay and whether there was consensus on which of the issues was the most important. In reply, Mr Cowe listed them as NHS reforms, standards of care, blood products and hepatitis; there was general agreement. Mr Taylor said that, while recognising the role of the Policy Committee as Mr Cowe had summarized it, the Society should persist in seeking to influence the outside world. The four issues mentioned had and would continue to have a major impact on people with*

> *haemophilia, and furthermore were inextricably linked with certain external organizations: for example, the issue of the availability of high purity blood products and their funding was an issue over which the Society needed to approach external organizations. This would directly affect the membership.*
>
> *In addition, all these organizations would certainly wish to talk to the Society itself and not through third parties. There was general agreement.*

20. Simon Taylor, who was an Executive Committee Member/Trustee of The Society from 1998 to 2002 provides evidence about the objectives, functions and challenges faced by The Society and its members before he became a Trustee and during his tenure at paragraphs 7 to 30 of his witness statement dated 22 April 2021 [WITN4500001]. Simon Taylor details that he believed The Society focussed on providing information and support to the haemophilia community generally until 1984/5. In addition, he felt, at that time, that whilst there were some centres of excellence in haemophilia care around the country, many people were receiving treatment from inexpert haematology consultants. However, The Society played a crucial role in addressing some of those problems. Simon Taylor details how he felt the community received valuable information through The Society's publications in respect of the care individuals should be receiving and The Society provided peer support networks. In addition, he states that The Society advocated for individuals and sought to educate key stakeholders.

21. Simon Taylor further details the impact of HIV on people with haemophilia and the way in which this affected the work of The Society:

> *[19] The Society at the time I joined was a very small, poorly funded organisation, working in small cramped offices and which had only relatively recently employed its first full time member of staff. It was funded primarily through community fundraising efforts such as raffles, coffee mornings, and sponsored activities by members.*
>
> *[20] The Trustees were then, and throughout the period I was involved, volunteers with normal full time other jobs and mostly were either people with haemophilia or the parent of someone with haemophilia. Many of the Trustees were also infected with HIV and continued carrying out their duties whilst ill, and in some cases until their death.*

> …
>
> *[22] Initially the most urgent need from the community was for information on the threat, and support and advocacy in responding to it. This was particularly in the context of the huge stigma and fear associated with HIV at the time.*
>
> *[24] Amongst the issues that the Society faced were:*
> *• Patients could not always rely on their treating physicians to give them accurate and timely information on the condition;*
> *• Much of what information that did exist was targeted at, and developed by, the gay community, and not appropriate for people impacted with haemophilia. Also, the haemophilia community did not want to be associated with the gay community or intravenous drug users;*
> *• A very great number of the Society's members were fearful that their haemophilia would be seen as a marker for having AIDS with the general public, and so often tried to keep their haemophilia secret;*
> *• Most significant of all, was the hysterical media coverage of the AIDS epidemic, with lurid stories which generated great distress and anxiety across the whole haemophilia community.*
>
> *[25] The response to these issues was a need for regular and rapid communication of information to people with haemophilia from a trusted and independent source. This became a core function of the Society, through The Bulletin', 'Update' and `Haemofact" newsletters, alongside the creation of such publications as "AIDS and the Blood" by Dr Peter Jones from Newcastle in 1985 and published by the Society.*

22. Simon Taylor also details some of the other work undertaken by The Society, for example, to lobby for the rapid introduction and use of safer products and the security of supply of factor products for the UK and a campaign to support all of those infected and affected. The support campaigned for by The Society was not only monetary but also for the necessary practical help, such as counselling and assistance with benefit claims. Simon Taylor also reiterates the evidence provided by David Watters in respect of the way in which The Society had to also deal with the media. Not only in responding to media queries, but also to allay concerns of The Society's members in respect of what was being reported by the media. Simon Taylor also stated, "*As the*

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

23. Karin Pappenheim, who was CEO of The Society from March 1998 to April 2004 states in her witness statement dated 14 May 2021 [WITN4504001] that at the time she joined The Society, its mission was stated as *"caring for people with haemophilia and other bleeding disorders"*. She cites a 1998 issue of The Bulletin, the first that was produced after she was appointed CEO (Exhibit HSOC0023022). She states that The Bulletin shows:

> *the range of services provided (page 12) for members, the scope of campaigning activities at the time relating to HCV and HIV, and the emerging issues around new variant CJD. As a national voluntary organisation, in common with other such bodies, the Society combined advocacy and campaigning with provision of support services for individuals and families. The charitable objectives of the Society did not change during my tenure, however the balance of resources allocated to advocacy, campaigns and provision of support services varied, depending on resources available and strategic decisions taken by the Board as to how to prioritise. This is typical of any such charitable organisations.*

24. It is a source of regret for me that we have not been able to make contact with Margaret Unwin, The Society's CEO from September 2005 to 2006. It would be wrong to speculate on her thoughts about The Society's aims and objectives in her time at the helm. But the fearless tone of her letters to Mr Connon, the head of blood policy, for example (see Exhibit HSOC0003560) perhaps evidences the importance she attached to lobbying and campaigning.

25. Medora Ann Hithersay, who was a Society trustee from January 2004 to December 2010, outlines at paragraphs 5 to 9 of her statement dated 2 February 2021 [WITN3206003] the objectives and functions of The Society throughout the time that she was a trustee. Ms Hithersay states that changes in focus by The Society *"occurred over time, in response to the challenges that members faced"*. At paragraph 9 of her statement, Ms Hithersay states that towards the end of her tenure, The Society *"remained focussed on the need to help families to treat newly diagnosed children with haemophilia, to ensure that they never became disabled in the way that had happened to many older people with haemophilia".* And The Society *"also wanted to*

ensure there was focus on the increasingly severe impact of Hepatitis C on their members, and appreciated the need for THS to campaign for more direct help to be made available to them".

26. A number of witnesses, including W1122, W5739 and W3988 have referred to feeling that The Society wanted to ignore or distance itself from those who had been infected and to focus on a younger generation of haemophiliacs that were not infected. The witnesses do not provide specific timeframes for when they felt this shift in focus occurred. I am very sorry that these witnesses feel like this and accept the validity of their perceptions. The Society *is* its members. The Society represents a diverse membership with a range of backgrounds and interests. At times, The Society has also been perceived as doing too much in relation to HIV. For example, I have been informed that David Watters has previously said that at one of The Society's Annual General Meetings, it was accused of being "The HIV Society". This shows that, at times, The Society has been pulled in both directions.

27. In accordance with the Inquiry's rules in respect of redaction, The Society is unable to name the many Society board members and trustees who themselves continued to use concentrates – that recommendation being rooted in the advice of Professor Bloom who appears to have spoken for all haematologists – and who also paid the ultimate price as a result. Many Society board members, trustees and members of staff, were themselves victims or had contaminated blood victims in the family. They were either themselves infected with or exposed to HIV, Hepatitis C or both, Hepatitis B, Hepatitis D, or their family members and loved ones were. Many of them died as a result of infected blood. This has been stated in evidence by witnesses including David Watters, Simon Taylor, Peter Wetherell, Andy Cowe, Keith Colthorpe, Karin Pappenheim and Roderick Morrison [WITN3429001, WITN4500001, WITN3912001, WITN3647001, WITN4430001, WITN4504001, WITN5252001]. The dates of death and obituaries in various editions of The Society's publication The Bulletin speak for themselves. Given their personal investment, it is difficult for me to comprehend that these trustees might have wished to *"ignore"* or *"sweep under the carpet"* issues relating to HIV and Hepatitis C infections.

28. I have seen an un-redacted version of a table of staff and trustees of The Society during David Watters' tenure, which was exhibited to his statement (Exhibit WITN3429006). Mr Watters was employed by The Society between 1981 and 1994.

Where individuals were employed or were trustees outside of these dates, Mr Watters has also included details of those dates for completeness. The table shows that:

a. Out of the total 30 staff members and Trustees listed, 16 were either themselves infected with HIV and/or Hepatitis C or had a familial link with someone that was infected.
b. Of the 25 Trustees listed, 15 were either themselves infected with HIV and/or Hepatitis C or had a familial link with someone that was infected.

29. In her witness statement dated 7 April 2021, Lucy McGrath (who was a hepatitis worker at The Society between 1997 and January/February 2001; and carried out administrative and project work between autumn 2001 to approximately July 2002) gives evidence about The Society's Hepatitis C campaign and makes reference to Society Trustees being personally affected [WITN5428001]:

> *[57] With regard to what extent the [Hepatitis C] campaign for compensation was informed by the views of the Haemophilia Society's membership, the Haemophilia Society was very user-led, and people affected by haemophilia and other bleeding disorders were very involved. Many Trustees were personally affected and the membership was heavily involved in campaigning (lobbying MPs, writing, petitions, sharing their personal stories etc.). The Haemophilia Society and the membership both wanted compensation and worked hard to try to make this happen.*

30. In his witness statement dated 25 February 2021 [WITN4503001], the late Jonathan Cooper (The Society's AIDS Co-ordinator for The Society from 1987 to 1990) wrote about the Trustees and their personal interests in the infected blood scandal:

> *[6] The trustees were remarkable people. Many of them still recalled the days before Factor 8, when their childhoods were marked by long periods of bedrest to control bleeds and all the associated pain linked with haemophilia. Many of them had spent time in the same school which specialised in managing haemophilia (amongst other conditions). They were fighters and survivors. There was a lot of humour — gallows- type humour. They also knew each other well.*

> *[7] These people were the beneficiaries of one of the great post war medical revolutions. Their lives became normalised. Pain became the exception and not the rule. And then the blood borne viruses came along.*
>
> *[8] By 1987, when I started to work for the Society, they had already gone through the first wave of hepatitis viruses. HIV/AIDS had become part of their everyday lives. They were not victims. They continued to be fighters and survivors, but they were weary. I compare them with a group of mighty warriors, who would still pick themselves up and be ready to fight the next battle. The Revd Alan Tanner offered wise leadership and men like Ken Milne were like great, experienced Generals. Ken knew exactly how to mobilise his forces, and they all cared so deeply about all people with haemophilia. David Watters was a loyal Colonel. He took his orders and went back into battle for them.*
>
> *[9] It was interesting to be reminded of the names of the Management Committee for 1988. Within years, so many would be dead. If they didn't die, their husbands or children did.*
>
> …
>
> *[25] The majority of the trustees were either living with HIV or their partners or children were. My role was to manage the HIV specific aspects of what the Society did.*

31. The Society's trustees at times, took different positions. Simon Taylor, who was co-infected with HIV and hepatitis C as a result of receiving infected blood products, gave evidence about the period of time when his strong view was that The Society could not afford to prioritise the Hepatitis C campaign, even though to do so would have been in his interests personally. Others disagreed. In keeping with what appears to have been The Society's approach throughout its existence to the resolution of important issues, the competing viewpoints were discussed and considered before a decision was made. And *"sweeping [Hepatitis C] under the carpet"* in order to ignore it was not part of Simon's reasoning.

32. W1122 does not indicate which trustees they had in mind nor do they indicate a time period. That makes it difficult to respond to the criticism. But as a general criticism, I cannot accept that this was the reality. There may have been times when The Society's actions were late, wrong or insufficient: that will be for this Inquiry to judge. But the fact that many people with haemophilia were living with HIV/AIDS or Hepatitis

C or both was not a matter that The Society ever *"ignored"* or tried to hide. It is fair to say that at all times after Society members started to become infected with HIV/AIDS and the emergence of Hepatitis C as a potentially disabling and fatal infection, The Society has had to try to meet the expectations of members with haemophilia who had one infection from contaminated blood, both infections or neither. I believe it is also important to note that all the while The Society was trying to help people who had been affected by infected blood products; it was being pulled in different directions also trying to help those with bleeding disorders who were not infected. The letters to the editor (as introduced in the editorial by David Evans) in the fourth edition of The Bulletin in 1998 illustrate this point well (Exhibit HSOC0023024).

33. The Society may not always have struck the right balance when trying to provide a service to all its members. However, there has never been a time when older generations of infected and affected people with haemophilia have been a source of shame or embarrassment to The Society. And there has never been a time when those members were regarded as historical relics whom The Society wished to background in order to focus on the young. I have not seen any evidence that this has been The Society's aim, intention or position in the past and it is not now. Neither am I aware of anything that The Society did or did not do from which it could be fairly inferred that The Society took this stance. To repeat, at all times since the 1980s, some of those running The Society or overseeing its work have themselves been victims of infected blood.

34. I now turn to comments made by W1122 that The Society's focus on a younger generation of haemophiliacs was driven by an idea that a *"new, uninfected generation of haemophiliacs were more presentable for fundraising purposes".*

35. Paragraph 13 of the written statement of Medora Ann Hithersay dated 2 February 2021 [WITN3206003] describes the governance structure around fundraising efforts:

> *[13] The Resources Committee was responsible for the overall direction of the funds of THS [The Haemophilia Society] so it would have been very much involved with fundraising efforts. We received a monthly budget from the finance department I believe. This was closely scrutinised, and the Chief Executive and the Fundraising Manager would provide information around budget variances. We would have discussed such things as the need to campaign for funds. We may have discussed the need to approach*

pharmaceutical companies but I cannot remember specific discussions about this, simply because the process by which we secure their funding, and the areas where they helped THS were already long established when I joined.

36. I have not seen any documents that indicate that The Society or the Resources Committee intentionally focussed its fundraising on *"uninfected generation of haemophiliacs were more presentable for fundraising purposes"*. I understand that this is the witness's belief but I am unsure what that belief is based on. I have not seen any documents that indicate that The Society or the Resources Committee intentionally focussed its fundraising on an *"uninfected generation of haemophiliacs",* and I have not seen any documents that indicate that the new, uninfected generation of haemophiliacs did raise more money than the older, infected generations. I am not aware of any material that suggests that The Society advantaged the young and/or uninfected unintentionally.

37. Looking back to the 1990s, I note The Society's first issue of The Bulletin in 1998 (Exhibit HSOC0019596) – where at page 18, Lucy McGrath put out a call to infected young people aged 12-21 asking them to get in touch to help with a booklet she was writing for those with haemophilia and Hepatitis C. This edition of The Bulletin also records the launch of a Hepatitis C petition, Factsheets produced by The Society about Hepatitis C and Hepatitis Support Evenings (referred to at page 10). I suspect, but do not know, that Lucy McGrath was writing a booklet for those aged 12-21 in order to cater to unmet need. In other words, that unlike other age groups, this age group had a need for age appropriate information, advice and support that it was not getting. I see this as evidence of The Society all the time trying to do its best by all of its members young and old, infected and not infected.

38. The Society has never been and is not a single issue pressure group. It represents all of its members affected by a bleeding disorder. That means that at all times, when considering how to allocate time and resources, it has to strike a balance between the needs of those directly caught up in the contaminated blood scandal and those who are not. In paragraph 2 of their statement, W1122 states that the objectives of The Society were "*to raise awareness of and provide support to those diagnosed with bleeding disorders, to raise money and to distribute this money to causes which would either advance research into bleeding disorders and their treatment or to assist those diagnosed".* W1122 states that these objectives did not change while they were a trustee from October 2014 to July 2015. These objectives remain to this day.

39. Throughout the process of drafting this statement, I have considered a number of Society documents. This includes documents that were both internal to The Society and also publications shared with its members. The documents indicate to me that The Society regularly engaged with and publicly reported to its members on issues related to HIV and Hepatitis C. Overall, my impression is that The Society was always dedicated to supporting, advocating and campaigning for people infected with HIV or Hepatitis C and their families. I refer to relevant documents throughout this statement and particularly draw the Inquiry's attention to the documents referred to under Topic 2 below.

Topic 2: The Society's advocacy and campaigning in relation to HIV, Hepatitis C and contaminated blood products

40. I have considered a number of documents that demonstrate some of what The Society did to provide information to and advocate for haemophiliacs infected with or affected by HIV/AIDS and Hepatitis C. I refer to these documents in the section that follows but stress that this is not an exhaustive list. The Society's range of activity was considerable and encompassed written publications, workshops, lectures, research and work with politicians ensuring that the contaminated blood scandal and Government's failure to deal with it was raised in the Commons and Lords repeatedly.

41. I am aware that some of our members are angry and disappointed by actions taken by The Society in the past. Some felt unsupported and believe The Society should have done more to help them. Amongst those people are W1122, W5739, W1055, W1056, W1791, W1210, W3988, W4120 and W3261. In this section, I address their criticisms about The Society's advocacy and campaigning in relation to HIV, Hepatitis C and contaminated blood products. Whilst I cannot respond to the personal experiences of these witnesses, I am very sorry for what they experienced and felt. I am very sorry they felt let down by The Society. I set out below a summary of these witnesses' criticisms before referring to documents that show the range of The Society's activities in relation to advocating for haemophiliacs who had been infected through contaminated blood products, again, stressing that this is not an exhaustive list. The criticisms include:

    a. W1122 believes The Society did not succeed as an advocate nor had it historically succeeded; W1122 believes that *"that the Society is good at talking about haemophilia without talking about the infections, and that it has failed to* *sufficiently recognise that for the last 45 years, it has been AIDS and HCV killing haemophiliacs, not their haemophilia"*;

b. W3988 refers to The Society being *"remote and out of touch"* in relation to campaigning on haemophilia and contaminated blood;

c. W1210 refers to a *"failure"* by The Society to support its members and the wider haemophilia community and an attitude that *"represents fear and a weak approach"*;

d. W1055 describes being told in 1994 by The Society that *"HCV was not an issue for their members despite the fact that we now had learnt that haemophiliacs had died and were dying of liver disease caused by hepatitis C"*;

e. W1055 refers to a *"substantial delay"* between the HIV litigation settlement and launch of the Hepatitis C campaign in 1995;

f. W1791 states that The Society *"were not interested"* in supporting people who had been infected with HIV – that they were *"the dirty secret"*;

g. W5739 believes that too little was done for, and on behalf of, haemophiliacs co-infected with HIV and Hepatitis C; W1055 also states that in 1998 they were told by the CEO of The Society that they do not campaign for people co-infected with HIV and Hepatitis C;

h. W5739 states that when it came to advocating for safe therapies on behalf of haemophiliacs, The Society had done *"too little too late"*. They state that, *"at worst, it could be argued the Society were complicit in the infection of thousands of haemophiliacs"*;

i. W1122 believes that The Society contributed to the scale of the contaminated blood products scandal and believes it would never be in The Society's interests to have a public inquiry which examined the causes and scale of the scandal;

j. W1055 and W1056 refer to the contaminated blood rally held in Trafalgar Square in April 2001 and feel that The Society's presence and support for this rally was not strong enough;

k. W1055 felt *"ostracised"* when attending The Society's AGM in Solihull in June 2001;

l. W1791 refers to a Reference Group Meeting held in 2015 to help inform development of the Consultation Document that the Department of Health planned to launch at the end of that year and feels that The Society were biased in relation to who they invited, calling into question The Society's integrity;

m. W1055 referred to The Society's involvement in the review of support schemes for the infected blood community which began in January 2016 and resulting in the government publishing *"Infected blood: Reform of financial and other support Prepared by The Department of Health, England"* and feels The Society contributed to *"putting forward who should be included which did not include fair representation of all groups and longest standing campaigners";*

n. W4120 criticises The Society for being party to *"conspiracies of silence"*; for a *"lack of action"*; and questions whether The Society acted in the best interests of haemophiliacs. W4120 states that The Society *"were party to the 'conspiracies of silence'. They were rightly concerned that haemophiliacs would refuse to take factor VIII products and of course worried about their patient risking AIDS infection, so they were struck between a rock and a hard place because the government did not act in response to the latter risk… It is debatable whether the Haemophilia Society acted in the best interests of haemophiliacs. They should have been able to reassure haemophiliacs that something was being done. But their lack of action in the face of risk, might not have been deemed dutiful or helpful."*

o. W3261 criticises that The Society was *"not sufficiently rigorous in pursuing the government and NHS for negligence in importing blood products from high risk groups"*.

42. The criticisms made against The Society are extensive but we do not shy away from them. In particular, The Society knows that its letter to members of 4 May 1983 (Exhibit BART0002365) was a mistake which certainly caused a loss of trust and which may have caused harm. The Society knows that this Inquiry's report will have some hard things to say about its shortcomings. Those will make for reading that is uncomfortable but necessary. The Society believes that a full and independent reckoning with its past is the only way The Society can hope to move forward with the support of as many of the haemophilia community as are willing to allow it a fresh start. The Society has provided approximately 30,000 potentially relevant documents to the Inquiry, and has voluntarily waived privilege over historic documents that may be of relevance to the Inquiry's Terms of Reference. The Society has voluntarily chosen to waive legal privilege to assist the Inquiry in being as open and comprehensive as possible.

43. The Inquiry has heard first hand evidence from David Watters that when the AIDS crisis struck, there were not the hours in the day or staff to devote to anything other than fire-fighting. But, so far as I can discern from everything I have heard and read, there has never been a time when The Society did not want a public inquiry and did want to avoid or evade scrutiny. The Society was always dedicated to supporting,

advocating and campaigning for people infected with HIV or Hepatitis C and their families. The documents set out below are only a few examples of the work The Society did to represent, advocate and campaign for haemophiliacs who had been infected through contaminated blood products.

44. A Society publication dating back to February 1983 titled "Group Seminar Proceedings" records that a group seminar was held from 12-14 March 1982 (Exhibit BART0002325). Group Seminar Proceedings reports on highlights from the workshops and includes articles written by some of the speakers at the seminar. At page 2, there is an article by Dr Brian Colvin titled "Haemophilia the State of Play 1982". In a section headed "Hepatitis", Dr Colvin states that hepatitis is caused by concentrate, discusses the non-A non-B variety of hepatitis, says that *"there is growing evidence that mild inflammation of the liver can continue after clinical recovery and the long term consequences of this are not yet clear"*, and notes that research is taking place to produce *"a low hepatitis risk commercial factor IX concentrate"*. I understand that at present, the next substantive document available recording work around Non-A and Non-B Hepatitis is May 1991 (see paragraph 56), a gap of around nine years. It will be a matter for the Inquiry to consider the reasons for the gap and any criticism that might be merited but clearly, the AIDS crisis hit in 1983 and that, and the resulting campaign for recompense, was all consuming for some years.

45. In June 1987, The Society published an edition of the Haemofact about "*AIDS and recompense for people with haemophilia*" (Exhibit WITN6392271). The Haemofact was a leaflet series produced and issued by The Society from time to time on topics of interest and concern to people with haemophilia. This edition provides information about support and help that is available to people with AIDS/HIV and sets the intentions for The Society's campaign for recompense:

> *As Society members will know from our earlier publications, we believe strongly that people with haemophilia who are HIV antibody positive deserve special consideration by the Government on account of their antibody status. We will be ready to launch our campaign for recompense when the new session of Parliament begins after the General Election. The House of Commons Social Services Committee Report on PROBLEMS ASSOCIATED WITH AIDS states that the question of recompense deserves careful consideration. As a result of our detailed investigations into the most appropriate form of recompense, it has*

> *become clear that our best chance of success lies in claiming a special weekly allowance.*

46. In October 1987, The Society made a submission to Government calling for financial provision for people with haemophilia infected with the AIDS virus, *"AIDS, haemophilia and the government"* (Exhibit BART0000603). In this document, The Society called on Government to do the following:

> *We are asking the Government to help restore the quality of life of people with haemophilia and HIV infection.*
>
> *At Government's suggestion the Society has already explored the question of redress through the legal system and has been advised that claims for compensation as such are most unlikely to succeed because of the difficulty of proving negligence. In any case, the Society is advised that any solution which may be provided by the courts will not be available in the short term. However, the needs of families are immediate.*
>
> *The Society is therefore looking to Government as the only available source of support, recognition and recompense.*
>
> *The Government should provide a weekly benefit to help all infected people with haemophilia and HIV to live with AIDS, a fund in recognition of the disaster which has befallen them, an insurance scheme to protect the home, and provision for dependants.*
>
> *The Society looks for an understanding response from the Government to help relieve the distress of those affected. This request is urgent; HIV infection has already placed an intolerable pressure on the lives of many of the infected families, who are a limited, clearly defined group, who by any standards, deserve compassionate treatment.*

47. There is a document titled "*AIDS and haemophilia: The hidden disaster*" written by Jonathan Cooper, AIDS Co-ordinator for The Society dated 23 October 1987 (Exhibit HSOC0004680). This document states:

The story of haemophilia and HIV is tragic. However, the Society and its members are no longer solely concerned with sympathy. The Society wants action. The Social Services Committee on problems associated with AIDS (1987) concluded that, "the needs of haemophiliacs deserved special consideration." People with haemophilia and HIV need help. The Government has suggested the Society go through the courts and seek legal redress. Whether negligence can be proved is a moot point. Yet, what is clear is that even if such legal action were successful any form of compensation would arrive too late for the litigants. At present sixty people with haemophilia and HIV have developed AIDS, forty-five of whom have died. These figures have doubled since the spring. It is still impossible to state that all those who have HIV antibodies will go on to develop AIDS, however, the signs are ominous.

The tragedy of twelve hundred people dying as a result of National Health Service treatment is a disaster in its own right. The Social and financial implications surrounding their infection and possible death place that disaster upon epic proportions. The Government is the only institution capable of minimalising the distress of all those concerned. It is for that reason that the Society is petitioning the Government to provide an insurance scheme, a benefit for widows and other dependents upon the death of the husband or breadwinner and also a weekly benefit to help cope with living with AIDS. There is also a claim for a solatium to be provided to help redress the unquantifiable emotional anguish caused by HIV infection.

The needs of people with haemophilia and HIV are urgent. The Society does not want to do battle with the Government over responsibility for the quality of blood products. Alternatively, the Society pleads for the Government to show compassion and to act responsibly. Dr. Peter Jones's leader in the British Medical Journal (17 October 1987 Vol 295 page 944) indicated how the Government could implement action immediately. As he points out, the 1978 Royal Commission on Civil Liability and Compensation for Personal Injury (The Pearson Report) and the 1979 Vaccine Damage Payments Act could provide government with ways forward in dealing with this chronic situation.

The Haemophilia Society therefore pleads that the Government stops prevaricating and acts swiftly to mitigate the distress of its members.

48. I have read the statement of Jonathan Cooper dated 25 February 2021 [WITN4503001]. Mr Cooper was employed between 1987 and 1990 as the AIDS Co-ordinator for The Society. His role was to manage the HIV specific aspects of what The Society did. At paragraphs 22 to 23 and 27 to 32 of his statement, Mr Cooper sets out specific efforts The Society made to support people with HIV/AIDS, including:

> *[22] The Society's function was to support its members and all people with haemophilia. It therefore engaged with all aspects of living with haemophilia, particularly in relation to healthcare, but most issues from schools to social services were part of THS's remit. And, then, of course HIV/AIDS also became central to what THS did.*
>
> *[23] HIV/AIDS was overwhelming the Society. They therefore fundraised and secured funding for the position that I was to be appointed to.*
>
> …
>
> *[27] A lot of what I did was delegated to me by David. I became THS's outward facing link with haemophilia and HIV. David literally didn't have time to do everything. I also supported David in his work. I kept him, and therefore THS, up to speed on HIV related issues from treatment to prevention. I worked very closely with him on the campaign for recompense.*
>
> *[28] I had various projects of my own. To highlight a few, these included explaining the benefits system for HIV, co-ordinating the first symposium on paediatric HIV and producing the first safer sex guide focussed on people with haemophilia. I also worked with HIV organisations on establishing a respite system for people with HIV/AIDS, drafting the Declaration of Rights for People with HIV/AIDS and developing systems of complimentary therapy for those who wanted it. There was a big demand.*
>
> *[29] I also monitored the Haemophilia Centres — a principal focus of that work was assessing how well HIV was managed within Haemophilia Centres.*
>
> *[30] In my last year at the Society, I was also seconded to the World Federation of Hemophilia. I drafted their materials on living with haemophilia and HIV. This meant that I would travel to Montreal (where it was based) and to Calgary, where a social worker that I worked with lived.*

> *[31] We were always having to respond to immediate issues. These could arise from the campaign for recompense, a news item or something like the US Government imposing a travel ban on people with HIV entering the USA.*
>
> *[32] My role was to give effect to THS's agreed policy linked to HIV/AIDS. My input was always welcome, but the trustees made the policy, not the staff. On issues relating to haemophilia treatment, I would have little or no involvement although I would be aware of the discussions. The trustees were the experts. To the extent that THS took a position on HIV treatments, David and I would offer our understanding of those treatments.*

49. At paragraph 184 of Simon Taylor's statement dated 22 April 2021 [WITN4500001], Mr Taylor refers to *The Guardian* article of 17 November 1987 (Exhibit WITN4500017), which sets out an account of the political aspects of the campaign for compensation for haemophiliacs infected with HIV/AIDS as a result of contaminated blood products and the steps taken to achieve the government's change in policy.

50. At paragraph 185 of the statement [WITN4500001], Mr Taylor refers to the "second phase" of The Society's campaign for compensation for haemophiliacs infected with HIV/AIDS as a result of contaminated blood products. In this phase, an initial £10m was granted by the government to establish the Macfarlane Trust. Mr Taylor states that this stage focussed on the *"moral imperative of the Government in providing recompense for the failure of government policy and formally continued until 1991, although we never accepted that the subsequent payments in 1989 and 1991 were in any way adequate compensation for the consequences of infection via blood products"*.

51. At paragraph 302, of his statement, Mr Taylor refers to Exhibits MACF0000002_003 and MACF0000002_004. Mr Taylor confirms that these documents show that The Society made grants on behalf of the Macfarlane Trust before the announcement of the award of £10m (referred to in the paragraph above) and the establishment of grant making process by the Trust. He states that the purpose of this was:

> *in order that there should be as little delay as possible in providing help and support in urgent cases. The alternative was that there would have been a six month period in which no payments were made. In my opinion I believe that this was a generous act by the Society to use its own funds to bridge the gap*

> *until the Trust was fully up and running. These funds were reimbursed by the Trust once it was fully established.*

52. It is clear from the documents that The Society saw the £10m provided for the establishment of the Macfarlane Trust as the beginning and no more than that. The fourth Bulletin of 1987 (Exhibit HCDO0000276_043) opened with the heading "*IT'S a START…*" with an article confirming that this was the first step in The Society's campaign. The Minutes of a meeting of the Executive Committee of The Society dated 8 September 1988 (Exhibit HSOC0029690_003) include the following extracts at page 2:

> *Treatment and care: … A meeting had also been held with the Medical Advisory Panel on the afternoon of 2 September 1988 at which, once again, the factor VIII supply question had been discussed along with questions arising from hepatitis B vaccine policy, monoclonally produced products, litigation and other issues of immediate interest and concern to people with haemophilia*
>
> *…*
>
> *The Treatment and Care Working Party had also met within the past few days and had discussed a possible conference on issues arising from HIV and AIDS in children and young people…*

53. Also, in 1988 there is reference in The Bulletin Number 3 (Exhibit PRSE0000056) to the Factor VIII shortage and the work The Society was doing to try and collate information in respect of this in order to find a solution to include continuing to lobby for self-sufficiency. The discussions continued and there is reference in The Society's August 1990 edition of The Bulletin (Exhibit HSOC0019591) to the following information relating to HIV and AIDS:
    a. Background and information on the "campaign for justice" for HIV infected haemophilia patients;
    b. A letter from "A.Patient" and the Centre Director's response regarding AIDS and factor VIII;
    c. An article, 'Psychological and social impact of HIV infection in men with haemophilia' written by Dr Jose Catalan;
    d. An article, 'Women and AIDS: Current knowledge';
    e. An article regarding rights and liberties as a HIV infected citizen in the UK/ This article was reprinted from 'AIDS MATTERS' (May 1990, issue 1).

54. At page 8 of The Society's August 1991 edition of The Bulletin (Exhibit HSOC0022976) there is an article titled "*A look at last year*", where reference is made to The Society's Annual General Meeting, during which the Chairman, Reverend Alan Tanner commented on The Society's involvement in the HIV litigation and The Society's associated campaign. Reverend Tanner is quoted in this article as saying:

> *One of the points to note from the past year was the conclusion of the HIV litigation. While acceptance lay with the lawyers, and the lawyers only, the outcome would not have been possible without the support of so many people for the Society's campaign.*

55. In the same article, there is reference made to The Society having introduced *"Haemofact HIV Treatment News"*, and this being *"warmly received"*. The same article also refers to an event that The Society arranged for women affected by HIV through their partners and notes that The Society was looking to explore new formats for conferences for families of those affected by HIV directly or indirectly.

> *In March the Society held its first weekend for women affected by HIV through partners, children etc., in Newcastle. A similar conference was held in Durham in April this year. The Member Services Committee are exploring new formats for conferences for the families of those affected by HIV directly or indirectly.*

56. The Society's May 1991 edition of The Bulletin (Exhibit RFLT0000056) contains an article titled "*Haemophilia and Liver Disease*" by Dr C.R.M Hay, Director of the Mersey Region Haemophilia Centre. Through this document, The Society provided its members with a detailed analysis of transfusion transmitted viruses, including providing information about Acute Non-A and Non-B Hepatitis; haemophilic liver disease; prevention and treatment.

57. A timeline of the work that The Society did in relation to campaigning for haemophiliacs infected with HIV/AIDS illustrates the extensive campaigning work that The Society did with respect to their Hepatitis C campaign in the period from 14 November 1991 to 29 November 1995 (Exhibit HSOC0015185). I acknowledge that the Birchgrove Group was a group specifically for people who were co-infected with Hepatitis C and HIV. Nevertheless, The Society's Hepatitis C campaign was also intended to benefit people who were co-infected with HIV.

58. The “Treasurer’s Statement” in The Society’s 1992 “Annual Report and Accounts” (Exhibit HCDO0000279_033) states:

> *As we reported in our Review of 1991 the large numbers of hepatitis infections in the past was a source of major concern. There have been no new infections since 1986/7 but it remains important to ensure that blood products in the UK are safe from hepatitis in all its forms. Important work is being carried out on treatment with Interferon and the future could be brighter for some of those infected, although unfortunately some have already died. Our role continues to be keeping everyone up to date with developments surrounding hepatitis.*

59. Minutes of a meeting of the Council of The Haemophilia Society on 29 February 1992 (Exhibit HSOC0019923_038) record that *“A comprehensive report on hepatitis had been submitted by Mr Taylor and Mr Dickason at the last meeting of Council at Sunderland, and the promised fact sheet would be forthcoming before long. Mr Milne said that the Society was keeping an eye on the matter and in particular the possibility of a claim for compensation through an individual group of solicitors. The Society's membership would be kept informed of any developments.”*

60. The same document records consideration of a weekend for young adults or teenagers affected by HIV. The document notes, *“This was a group that had considerable problems in coming to terms with the condition and it was hoped that a weekend might be arranged in early 1993.”* The document also notes that although hopes were expressed for a weekend for those families affected by HIV this “*would have to be held in temporary abeyance as there has been a hitch in funding but the weekend was planned for Easter 1993.”* This illustrates that The Society’s will to provide services for its members affected by HIV was at times curtailed by funding restrictions.

61. Minutes of a meeting of the Council of The Haemophilia Society on 21 November 1992 (Exhibit HSOC0019923_040) record discussions about concerns regarding cuts to funding and the effects on high purity blood products and the need for The Society to understand what was happening on a local level for its members:

> *Mr Taylor reported that he felt the Society was about to encounter a range of problems that were potentially as serious as the HIV/AIDS crisis. He said that the transition from intermediate to high purity blood products was threatened*

> *by cost-cutting. It was recognised that treatment with high purity products was beneficial, especially for those with HIV, and this view had the backing of the Centre Directors. However, funding was being cut back for these products and the Government and Regional and District Health Authorities were examining how much haemophilia care cost in comparison with, for example, hip replacements. Mr Taylor said that treatment of haemophilia was expensive. He urged people to let the Society know if their treatment was being changed, and said that the Society needed to be aware of what was happening at a local level.*

62. At page 10 of The Society's August 1993 edition of The Bulletin (Exhibit HSOC0022993), there is an article titled "*Quilts, claims and counterclaims: How to survive the Berlin AIDS conference*" which reports on a number of events, research studies and issues discussed at the Berlin AIDS conference. This edition also introduces Liz Cox, a Social Worker from Barnardos who was available *"to assist families where one or more members have haemophilia and HIV"*.

63. Notes of a meeting of the Hepatitis Task Group on 16 September 1993 (Exhibit HSOC0003289) record that it was agreed *"that the most valuable roles which could be provided by the Society lay in the provision of accurate and up to the minute advice and information and an ongoing lobby to ensure the very best levels of treatment and care of people with haemophilia and hepatitis in any/all its forms along with support for those who are and become ill. The information aspect could be achieved particularly through our regular publications but also through the booklet on hepatitis prepared, and now finalised"*

64. The meeting then went on to discuss recommendations for a Hepatitis Awareness Campaign for people with haemophilia. After discussion, *"a format was agreed whereby a series of meetings could be held at seven venues throughout the UK where medical and legal aspects of hepatitis would be presented at a three hour meeting which would also include time for Q&A's. Venues for the meetings could be:- Perth; Craigavon, York, Manchester, Birmingham, Bristol, London."*

65. Minutes of the Executive Committee meeting on 29 to 31 October 1993 (Exhibit HSOC0023737) make reference to the importance of publication of a Hepatitis booklet and planned meetings around the UK allied to publication of the booklet.

66. In addition to the examples of correspondence, meeting minutes and publications above, there is reference in The Society's November 1993 edition of The Bulletin (Exhibit HSOC0022994) to the transmission of Hepatitis C and HIV to family members. At page 5 of this document, there is an article titled "*Viral Transmission of Hepatitis C and HIV in partners of people with haemophilia*". The article provides an update on research by Dr Telfer at the Royal Free Hospital which concluded that heterosexual partners of haemophilia patients do not carry an exaggerated risk of Hepatitis C infection. At page 12 of the same edition of The Bulletin, there is an update on "Haemophilia and Hepatitis C" from the British Society for Haematology annual scientific meeting.

67. On the front page of The Society's April 1994 edition of The Bulletin (Exhibit RFLT0000071) there is an article titled "Hepatitis C – A cause for concern?" written by Simon Taylor. In the opening paragraph, Mr Taylor comments that *"It is now clear, with the advent of the [Hepatitis C] test, that virtually everyone who has been treated with clotting factor concentrates, prior to the introduction of processes such as heat treatment to destroy viruses in the mid 1980s will have come into contact with the hepatitis C virus".*

68. The article goes on to describe some of The Society's work at the time with regard to hepatitis:

> *The Haemophilia Society is following developments in hepatitis closely, liaising with our medical advisers and encouraging the provision of more information and research. On Saturday 12 March, the Society held the first of what may be a series of meetings devoted to hepatitis. Dr Christine Lee from the Royal Free Hospital, gave a talk and answered questions on the issue. In addition the Society has published a booklet on hepatitis which is freely available by contacting the Society's office.*

69. At pages 12 to 13 of the same edition of The Bulletin (Exhibit RFLT0000071), there is a two page article by Graham Barker, Director of services and development titled "*What do members want from The Haemophilia Society*". The article refers to a survey of what members want from the Society. It notes that "*the clear message coming from the survey was that people wanted information and that they wanted contact and support*". In response, the article states that The Society would *be "looking at ways of providing information and support to people affected by hepatitis C".*

70. Minutes of the Executive Committee of The Society held on 7 May 1994 (Exhibit HSOC0000447) record that following a meeting between representatives of the Birchgrove Group and members of The Society's Executive Committee, it was proposed that the Services Committee establish an HIV Task Group. The following update was provided under the heading "Hepatitis":

> *The pilot Hepatitis meeting and the article in the No: 1 issue of the Bulletin has generated a good response and members have contacted their local Centres for more information. A second Hepatitis meeting has been arranged for Saturday 21 May in Leeds. Dr Makris and Professor Preston from Sheffield have been invited to be the speakers. The format for this day has been changed to allow smaller group discussions to take place. Other Hepatitis meetings will be held before the summer. Possible venues are Edinburgh on 25 June and Bristol.*
>
> *The issues of medical negligence and claims for compensation are being closely monitored. Work on hepatitis is overseen by the Task Group who will make sure that people have as much information on Hepatitis as possible.*

71. On 20 May 1994, Graham Barker circulated to The Society's Executive Committee a letter that Simon Taylor wrote to a member of The Society who had been *"pressing the Society to do more for people with haemophilia infected with hepatitis"*. (Exhibit HSOC0023425). This letter, dated 16 May 1994, makes for very stark reading, but is a letter of its time and reflects the thoughts and position of the time:

> *Let me say from the outset that the Society takes the issue of hepatitis very seriously. It affects virtually every seriously affected person with haemophilia over the age of ten in the country, in one form or another. I also have to say from the outset that we are faced with some very difficult problems in responding to hepatitis, in many ways the situation is much more complicated than for HIV.*
>
> *You are quite correct in that hepatitis was transmitted in the same way as HIV, in infected blood products, but the situation from a campaigning point of view presents us with some problems. I should like to address these first and then move onto those areas where I believe that action can be taken.*

In the case of HIV, the group who have been infected are all expected to in due course become seriously ill and probably die as a result of their infection. In the case of hepatitis, current thinking is that a relatively small proportion will develop serious problems, the vast majority will remain well, and indeed have been well with hepatitis for perhaps twenty years. The Government and indeed the general public will find it difficult to have great sympathy with a group who are not seriously ill and are not likely to become ill.

Another issue is that a central element of the HIV campaign was that the Government contributed to the infection, because it had not instigated a policy of using only UK produced blood products. This would not have made any difference in the case of hepatitis since as many people have been infected from UK blood products as from imported ones.

The situation as far as litigation is concerned is a complex one, and I am not a lawyer. In any case it is necessary to show negligence and loss. I believe that it would be very difficult to show that, in the case of someone with severe haemophilia, a doctor had been negligent to treat them with blood products, we all know the consequences of failing to treat bleeding episodes, and no safer products were available.

In addition, in the majority of cases, loss has not been suffered as a result, in that they are well and remain so. In addition, as you will be aware, those who have accepted the HIV settlement are debarred by the settlement reached by their lawyers from taking further actions.

This means that the best possible cases are those where treatment with blood concentrates was an option, usually in people with mild or moderate haemophilia, and those cases where people were treated with non-heat treated products when they were available. This will be a small number of cases.

I have to say that I am no happier with this state of affairs than I am sure you are, but they are the facts of the matter and there is very little that we can do about it.

> *Let us move onto the positive side of things as to what can be done. First of all, I believe that it is most important that everyone has as much information on hepatitis as possible. Again regrettably, there is a real shortage of information, particularly on Hepatitis C, which has only relatively recently been identified. As you will have heard at London and at Leeds, work is taking place on this, but we do not yet know all the answers.*
>
> *It is most important that centres give out as much information as possible to patients, and it was for this reason that I wrote the Bulletin article, in order to encourage people to ask their centres about hepatitis.*
>
> *The Society cannot take the place of each individuals own doctor. The Hepatitis meetings are designed to give people another source of information, so that they can again go to their own doctors for more information and advice.*
>
> *You express dissatisfaction with our booklet, which sets out most of what we know, if you would like to let us know questions that you would like answered that it does not cover, please let us know and we will try to find out the answers if we can.*
>
> *My own personal view is that an area where we might be able to make some progress with the government is to extend the scope of the Macfarlane Trust to be able to provide financial assistance for those who are suffering serious health problems as a result of hepatitis.*
>
> *The final area where we can take some action, and we already are, is to pressure centres to improve their care of people with hepatitis, and ensure that haemophilia centres are aware of the latest information on hepatitis and its treatments.*

72. Minutes of an Executive Committee meeting on 7 July 1994 (Exhibit HSOC0024847) note that the Hepatitis Task Group would meet to review meetings held around the UK. The minuted record states, *"Major issues arising from these meetings include the lack of information given by Centres; the failure to notify people that they are HCV positive; the range of liver tests that are available; access to interferon and the life style that should be pursued. The Task Group will consider what action to take and*

will also discuss the medical negligence and compensation issues raised by Mr Peter Mossman."

73. In the editorial section of The Society's October 1994 edition of The Bulletin (Exhibit HSOC0023000), Andy Cowe, editor of The Bulletin at the time, commented on the limited medical knowledge of Hepatitis C and its effects and notes that The Society *"is actively seeking to spread the knowledge which does exist":*

> *Medical knowledge of the hepatitis C virus (HCV) and its effects is still at an early stage and much work remains to be done in identifying the progression of liver damage caused by the HCV and in developing treatments. The Society is actively seeking to spread the knowledge which does exist.*

74. In the same section, Mr Cowe goes on to introduce the article at page 8 of the publication – which is a whole page dedicated to a Q&A about Hepatitis C by Dr Mike Makris. Again, he refers to The Society's dedication to keeping its members updated about the latest information in this area:

> *Dr Mike Makris' article on page 8 and 9 provides a valuable set of answers to some of the most important questions in this area. The Society is pledged to keep our members and readers of the Bulletin up-to-date with the latest additions to knowledge in this field.*

75. Dr Makris' article on page 8 notes that the *"Hepatitis Days held up and down the country to inform people with haemophilia about hepatitis C were very well received by those attending".*

76. A minute of the meeting of The Society's Services Committee on 10 November 1994 (Exhibit HSOC0023353) records differing opinions given by Executive Committee members about a proposal from the Hepatitis Task Group for a Hepatitis C publicity campaign whose objective it would be to gain better treatment and care for those infected and financial help from the Government as and when those infected became ill. It is clear from the minutes that there was no straight forward solution and The Society considered all potential arguments in support and in opposition to the Hepatitis C campaign:

Andy Cowe expressed the view that the damage that such publicity would cause to the Haemophilia community would outweigh any gains. A high profile campaign was not a suitable solution. He stated that a 'halfway house' solution may be the best way forward. It would be necessary to define what the Society wished to acquire. He suggested that the answer may lie in a Macfarlane Trust type of organisation. He underlined the necessity for a dialogue between the Society and the government.

Chris Hodgson felt that it would be difficult to place the blame on anyone as the HCV infection has been taking place since the 1970's, and that therefore it would be difficult to win compensation.

Mark Winter raised the issue of the complexity of HCV and stated that there is not sufficient knowledge about it. His view was that increasing public awareness creates a risk of causing panic and discrimination. The Society should discuss the issue with the Department of Health, and its priority should be to seek the best medical advice for its members, which should include funding research and making sure that members are counselled on diagnosis.

Norma Guy suggested that the Society would have to be seen to be actively dealing with the issue of hepatitis otherwise members such as the Manor House Group may approach the press themselves.

Dr Evans felt that the Society needs to put pressure on doctors to provide those infected with information about the virus. Compensation was not, in his view, a feasible option at this early stage. The Society should gradually feed the population with information regarding hepatitis, which would be both informative to the general public and satisfactory action for the Manor House Group.

Keith Colthorpe expressed the fear that in the public eye hepatitis would take on the same dimension as HIV, and stated that the Society should discourage people from pursuing the idea of litigation.

Simon Taylor concluded the discussion by suggesting that the Society should make it clear to ministers and the Department of Health that it takes the situation extremely seriously. Pressure should be put onto them, possibly

> *through occasional media coverage. A high profile campaign was not yet appropriate.*
>
> *Andy Cowe strongly expressed the opinion that once the media had a story they could not be controlled.*
>
> *Norma Guy expressed concern regarding the dissatisfaction of the Manor House Group, if the Society was not seen to be doing something.*
>
> *In response to this David Evans stressed that the Society was clearly attempting to provide more information and promote better treatment for its members.*

77. In her statement to this Inquiry dated 27 April 2021 [WITN5251001] Norma Guy (who was a member of The Society's Executive Committee between 1991 to 1996 and also a member of the Manor House Group) states at paragraphs 88 to 90 that she believes it was after this meeting that The Society began campaigning for compensation for haemophiliacs infected with Hepatitis C as a result of contaminated blood products. She believes that pressure from the Manor House Group and those who were directly affected is what prompted The Society to do so.

78. The Minutes of The Society's Executive Committee meeting on 18 November 1994 (Exhibit HSOC0029690_045) include a report of discussion by the Services Committee on Hepatitis and press coverage on compensation for people with haemophilia and Hepatitis C:

> *At the recent meeting of the Services Committee Mr Taylor reported that the press had information on Hepatitis C and haemophilia, and that there could be some press coverage on compensation for people with haemophilia who had contracted Hepatitis C through blood products.*
>
> *The Independent newspaper, subsequently ran the story and approached Mr Taylor for a statement on the Society's position. Mr Taylor reported that the Society had no plans to seek compensation. He explained that there were many uncertainties about HCV and the Society was actively seeking more information. A press statement prepared in consultation with the Chairman was released and circulated to the media and the Department of Health to confirm*

Mr Taylor's statement. The articles had caused concerns amongst members of the Society, Centre Directors and Pharmaceutical Companies. Although the press coverage was anticipated, the scale of it was unexpected.

Mr Barker expressed concerns that the Society may lose credibility with certain organisations including the Department of Health and the British Liver Trust. It was important that the Society had a clear statement about what it intended to do. In view of this Mr Taylor drafted a policy statement. The Committee approved the statement and agreed that it be presented to Council for their approval. The statement would then be circulated to the DOH. British Liver Trust, the press and the media. The policy statement as drafted and read by Mr Taylor is:

"The Haemophilia Society is seeking the maximum help for people affected by hepatitis as a result of their NHS treatment.

There is considerable uncertainty in the area of prognosis and treatment of hepatitis.

We intend, as a priority, to press for help for those most affected, that is, the families of those who have died and those who are suffering illness as a result of hepatitis.

We will discuss with the government financial help for this group.

We will seek to ensure that haemophilia centres have all the resources necessary to ensure the best possible treatment and care for people with haemophilia and hepatitis.

We will press the medical and scientific community for urgent and thorough research into the prognosis and treatment for hepatitis".

79. On 23 November 1994, The Society published a newsletter (Exhibit HSOC0005112_001) setting out the facts about Hepatitis C for its members and the action that The Society had taken and would be taking in the future. This document shows that The Society was trying to tackle Hepatitis C from a number of different angles and its work was not limited to campaigning alone:

Action by the Society

Over the last two years the Society has been responding to HCV in a number of ways.

Last year we produced a booklet, explaining hepatitis in the context of haemophilia. This is being updated and will be available shortly from the office.

Every Bulletin has contained the latest information on hepatitis, and will continue to do so.

Hepatitis meetings have been held throughout the country, providing an opportunity to hear from medical experts about the impact of HCV. More are being planned for 1995.

At our request, the Haemophilia Centre Directors are developing a treatment protocol for HCV.

We are supporting a major meeting of liver specialists and haemophilia treaters being held in two weeks time.

We have held discussions with the Association of British Insurers about the problems with life insurance.

In addition to these activities, we will be seeking help from the government in a number of areas.

- *Equitable treatment in financial terms to alleviate the hardship suffered, between those who are ill with hepatitis and families of those who have died, with those who have been infected with HIV.*

- *Haemophilia centres need to have the resources required to provide the best possible treatment and care for people with haemophilia and hepatitis. These would include:*

> *Access to the highest possible purity blood products (monoclonal or recombinant) both on grounds of reassurance of product safety and to reduce the immunological load on patients with HCV.*
>
> *Resources to provide counselling and support services for people with HCV.*
>
> *Resources to pay for interventions and treatments, such as Interferon, should they be required.*
>
> *Ensuring that haemophilia centres work closely with specialist liver units, particularly in the undertaking of liver biopsy or transplants.*

• The Department of Health must ensure as a top priority, that in all its communications with the public, it provides re-assurance about the methods of transmission, and how social contact is not a means of transmission.

• The Department of Health must encourage and provide additional resources for research into the prognosis and treatment of hepatitis

Everyone should be assured that the Society is taking every possible step to protect the interests of its members. The fight may take some time, but we will always keep you up to date on progress.

80. Minutes of The Haemophilia Society's Executive Committee meeting (Exhibit HSOC0023623) on 1 December 1994, record that not everyone supported The Society's Hepatitis C Campaign. The minutes record that there was a proposed amendment made to minutes of the Executive Committee meeting on 21/22 October 1994 regarding the Hepatitis C Publicity Campaign. It was agreed that the following amendment (which had not been included in the minutes) would be added: *"Mr Pepper stated that he (on behalf of the Northern Group and himself) wished to record a strong objection to any high profile lobbying or publicity campaign that may be initiated by the Society, on the grounds of the possible stigma to and detrimental effect on the prospects of younger boys."* The same minute records The Society's activities in relation to the Hepatitis C campaign, including:

    a. Press coverage and a statement made by Simon Taylor;

b. A meeting between Simon Taylor, Graham Barker and the Department of Health to informally raise the question of financial help to alleviate the hardship suffered by people with Hepatitis C and families who have died. The minute states, *"Discussions took place to provide additional resources for research into the prognosis and treatment of Hepatitis C; counselling and support service; and also to set up a hardship fund. A close relationship will continue with the Department and further development will be reported to the Committee."*

c. A Hepatitis Campaign group, comprising the Chairman, Mr Taylor, Mr Hodgson and Mr Barker being set up to address hepatitis issues. The minute states, *"the Group will meet regularly and have invited Mark Weaving at Health Network and Rory Chisholm and David Candlin from GJW, a leading firm of lobbyists who played an important role with the Society in the HIV campaign to participate."*

81. Later in 1995, the same year as the Government's Hepatitis C look back exercise was announced, The Society launched a campaign for Government help for people infected with Hepatitis C. The Society's March 1995 edition of The Bulletin (Exhibit HSOC0022985) reports on the front page that speaking at the launch, The Society's Chairman at the time, Rev Alan Tanner said:

> *Over 3,000 people with haemophilia have been infected with this potentially life-threatening virus through treatment with clotting factor concentrates before 1986 and over 40 have died. They were infected in exactly the same way as over 1,200 people with haemophilia contracted the HIV virus – through treatment with contaminated blood products. Yet while those infected with HIV receive financial help from the Government those with hepatitis C are receiving nothing.*

82. On the same page, the document explains that the campaign's objectives were:

- *More equitable treatment in financial terms between those people with haemophilia infected with hepatitis C (HCV) through contaminated blood products and those infected with HIV through contaminated blood products, specifically:*
    - *An across the board ex-gratia payment to all those infected with HCV through contaminated blood products.*

    - *Access to a hardship fund for those who become ill and the dependants of those who die.*
    - *As a matter of urgency, payments to those who are already ill and the dependants of those who have died.*
- *Adequate resources for haemophilia centres to enable them to provide the best possible treatment and care for people with haemophilia and hepatitis.*
- *Adequate resources for research into the prognosis and treatment of HCV.*
- *A public education programme that provides reassurance about the methods of transmission of hepatitis C and explains that ordinary social contact is not a means of transmission.*

83. The same article also reports that The Society had been successful in *"persuading the Government to give some funding to support research into the effects of living with hepatitis C."* It also persuaded the Government to undertake research into the effects of living with Hepatitis C and Mandy Cheetham was appointed to undertake a survey of members and produce a report. When Lord John Horam (former Parliamentary Under Secretary of State for Health, 1995-1997) gave evidence to the Inquiry, he commented on the impact The Society's report had on him, *"… when I had the opportunity to read this, I mean one is struck by the awful consequences of the condition. And I also knew from my constituent the difficulties he faced. So I just had total sympathy for the people involved."* The year 1995 also saw publication of The Society's book on Haemophilia and Hepatitis C. Documents reporting on these events are set out below.

84. In Andy Cowe's editorial in the same edition (at page 2) he commented on the intentions of the campaign; the progress made so far; what needed yet to be done and its significance:

> *The launch of the hepatitis C campaign is only the beginning of the Society's efforts to get fair treatment for people with haemophilia infected with the hepatitis C virus. There is a long way to go before we can convince the Government that they have a moral duty to help.*

> *A good start has been made, with questions and debates held in the House of Lords but we also need to apply pressure through Members of Parliament. To do this needs the support of members of the Society as a whole…*
>
> *People with haemophilia were infected with hepatitis C (HCV) in exactly the same way as those who were infected with the HIV virus. Hepatitis C is a life threatening condition that also seriously affects the quality of life for those infected. People may not go on to develop serious liver damage, but equally they do not know if they will. This uncertainty can have a bad effect on the lives of people infected with the virus, who cannot confidently plan for the future.*
>
> *The Society accepts that while there are some differences between the HIV and HCV infections, the similarities are strong enough to warrant the Government accepting its moral duty to help those people with haemophilia infected with HCV.*

85. The same issue of The Bulletin also includes:
    a. A summary of the Guidelines on the Diagnosis and Management of Hepatitis C that was produced by the working party on chronic liver disease in haemophilia of the UK Haemophilia Centre Directors' Organisation (at page 3);
    b. Information about a new HIV and AIDS treatment directory, as part of the National AIDS Manual (at page 3);
    c. Under the heading "Hepatitis C Litigation – Time limits for making claims", information about time limits for applying for a possible claim for medical negligence (at page 5);
    d. A response from Dr Charles Hay to a question about whether "*the hepatitis C virus [can be] spread by clearing up blood spillage, such as from a child's nose bleeds*" and advice on what precautions should be taken (at page 8);
    e. A report of The Society's Conference in Coventry that took place on 19-20 November 1994. The report says that *"the highlight of the conference"* was a session by Dr David Mutimer from Queen Elizabeth Hospital in Birmingham on hepatitis C – *"For many of those attending this was their first chance to hear a liver specialist talking in detail about hepatitis C"* (at page 11)

86. The Minutes of The Society's Services Committee meeting on 12 April 1995 (Exhibit HSOC0023343) record that on 14 March 1995, The Society's Hepatitis C campaign

officially launched. The document records the basis of the campaign and sets out what The Society was calling for:

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

87. The minute continues:

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

88. The same document (Exhibit HSOC0023343) records that on 7 April 1995, the Hepatitis Task Group held a meeting chaired by Andy Cowe in Simon Taylor's absence. The document records that at the meeting:

   a. Mandy Cheetham was appointed as the Hepatitis Worker:

> *She would be attending the Hepatitis Day on 6 May 1995. Her role would include researching the use of Interferon treatment, as well as the issue of the extent to which centres were following the guidelines set out by the HCDO. She would be talking to people with hepatitis to find out how they were affected and what problems they were experiencing. This information would help define exactly what a hardship fund would be used for.*

b. The Hepatitis booklet was discussed and it was reported that the final draft was currently being circulated with a two week response deadline. It was agreed that a print run of 8,000 copies would be produced.

89. The Hepatitis booklet, titled "Haemophilia and Hepatitis C" was published in 1995 (Exhibit HSOC0017348). The Foreword (at page 2) sets out the aims of the publication:

> *This publication aims to bring the latest information about hepatitis C to as wide a range of readers as possible, both within and outside our own membership. We are also aware that many questions about hepatitis C remain unanswered, and the Haemophilia Society is active in urging the health sector to carry out essential research in these areas.*

90. The Introduction (at page 3) builds upon these aims:

> *The aim of this booklet is to help people with haemophilia, and their families, to understand HCV and the implications it has for their lives. Despite being infected with the virus, many people remain well for many years and, we believe, will continue in good health. However, a significant minority will suffer some, possibly severe, illness as a result of infection.*

91. Further information regarding Hepatitis C and HIV was contained in The Society's June 1995 edition of The Bulletin (Exhibit HSOC0022986) As follows:

a. The Society's Hepatitis C Campaign (at pages 1, 2 and 8), including an all-party meeting of MPs taking place in the House of Commons on 26 April 1995 and a resulting Early Day Motion being put down in the house calling for the government to provide the same help to people with haemophilia infected with Hepatitis C as for those coinfected with HIV;

b. The Society's Hepatitis C research and appointment of a hepatitis research worker, Mandy Cheetham to commence work on 7 June 1995 (at page 3);
c. An article by Dr Chris Ludlam about liver biopsies which refers to their role for individuals with Hepatitis C (at page 4);
d. News from the Manor House group (at page 11);
e. Information about Hepatitis C and life insurance (at page 11);
f. An update about Birmingham Hepatitis Day on 6 May 1995, which was attended by Dr Mike Makris and Dr Geoffrey Dusheiko and where Graham Barker gave a Hepatitis Campaign update and was *"inundated with questions"* (at page 12).

92. At page 6 of the same edition of The Bulletin, the "Red Ribbon Page" sets out some of the highlights of an Executive Committee resolution on Haemophilia and HIV:

> *The Haemophilia Society will demonstrate its support for people with haemophilia and HIV by undertaking a range of activities. The society will support self help initiatives for people with haemophilia and HIV and their families and seek to gain access to services provided by other agencies that are of benefit to people with haemophilia and HIV.*
>
> *To achieve these objectives the Society will endeavour to do the following:*
> - *encourage the Birchgrove Group to continue its work in developing regional networks of self help by providing practical and financial support; work with other HIV agencies to discuss common concerns and if appropriate share platforms with them;*
> - *work with haemophilia centres and individual staff to ensure that funding for HIV work is maintained and encourage their support for local self help initiatives as part of a national network;*
> - *encourage the Society's local Groups to become more "HIV friendly" and provide more support to those who have haemophilia and HIV, and their families;*
> - *Give greater prominence to HIV issues in the Society's publications*

93. The Minutes of The Society's Services Committee meeting, 16 November 1995 (Exhibit HSOC0023327) provide an update on The Society's Hepatitis Campaign.

Notably, it updates on the support and attention The Society's work had garnered from politicians and the media and a strategy for gaining further public attention:

> *It was reported that Alf Morris's Early Day Motion was retabled on 15th November. The motion has attracted 233 signatures from MPs. Only 3 MPs signatures were lost from the original list. Other MPs will be contacted for their support. An article about the campaign and the motion was also published in the Daily Telegraph on 15th November. Simon Taylor and Mark Weaving are working on approaching a major newspaper to publicise the campaign. Mark Weaving has also set up 8-10 interviews with the local and regional press for people to talk about their personal experience of HCV.*

94. The same document also makes reference to the following work The Society was doing in relation to Hepatitis C, HIV and blood products:
    a. Mandy Cheetham's post was extended to enable her to continue her research, in which she aimed to "*examine the impact of Hepatitis C on individuals; visit more centres; address the problems of access encountered by youths; extend her research to a more broad geographical spread*" (at page 2);
    b. Mandy Cheetham would produce a number of fact sheets;
    c. It was reported that the London Hepatitis meeting had been successful and 80 people attended. The document notes that "*The meeting proved that there was still a strong need for information.*" (at page 2);
    d. The HIV Task Group reported that in connection with World AIDS Day, a greeting card would be sent to members to help raise awareness. A grant of £750 from the Department of Health had been received, and the Birchgrove Group agreed to cover the cost of producing the card (at page 3);
    e. The HIV Task Group discussed Guidelines on Good Practice for HIV Treatment and content for future editions of The Bulletin (at page 3);
    f. In relation to blood products, *"Dr David Evans had redrafted the Society's Policy Statement which would be reconsidered at the Executive Committee on 29th November and submitted to the MAP for information… It was agreed that more pressure needed to be applied in order to change the decision to impose VAT on recombinant products. It was suggested that a letter be sent to the Chancellor before the next budget, November 28th and released to the press. The European dimensions would also be investigated.*" (at page 4)

95. The Society's December 1995 edition of The Bulletin (Exhibit HSOC0022988) provides the following further information relating to Hepatitis C and HIV:

a. The Society's Hepatitis C Campaign (at pages 1 to 2), including an interim impact report by The Society looking into the effects of Hepatitis C and haemophilia being published and copies being sent to Ministers, MPs and the press and a meeting between the Manor House Group and the Secretary of State for Health, Stephen Dorrell;
b. A note in Andy Cowe's editorial that The Society's research activities had increased in the area of Hepatitis C (at page 2);
c. Information about the availability of solicitor's notes regarding one member's successful claim for medical negligence after injection with Hepatitis C (at page 3);
d. Vaccination for people who have haemophilia and are HIV positive (at page 7);
e. Updates about Hepatitis meetings; the Hepatitis C Booklet and the Manor House Group (at page 11).

96. On 29 January 1996, Paul Pudlo at the Department of Health wrote a letter to Graham Barker, who at the time was The Society's Director of Services and Development (Exhibit HSOC0014304). This was a response to Mr Barker's letter of 19 December 1995. In this letter, Mr Pudlo responded to a number of matters and concerns raised in Mr Barker's letter dated 19 December 1995 regarding haemophiliacs with Hepatitis C. In particular, it appears that as a result of Mr Barker's letter, the Department of Health undertook investigations of cases where people had experienced difficulty in gaining access to Alpha Interferon. Mr Barker summarised the findings based on information made available to the Department by relevant health authorities and Trusts. In each instance, it was confirmed that Alpha Interferon would be made available in each of the cases raised by Mr Barker.

97. The Society continued campaigning for people infected with Hepatitis C for many years. The Society's HQ Magazine (Issue 3, Spring 2004) (Exhibit WITN6392272) reports on The Society's "mixed response" to the details announced on 23 January 2004 by Health Secretary John Reid of the Hepatitis C ex gratia payment scheme. The article reports that, *"[John Reid] revealed that that the Department of Health will make payments to everyone in the UK (including ex patriots) who was infected with hepatitis C through NHS treatment with blood and blood products and was alive on 29 August 2003. This means that relatives of those who died before that date will receive no payments."* The Society's Chief Executive at the time, Karin Pappenheim

is quoted as saying, *"The good news that government has decided to act to provide some financial recompense is sadly blighted by the exclusion of over 230 bereaved families who have suffered most and the insufficient level of payments. Our campaign for justice for the victims of this medical disaster must go on."* The article provides information about eligibility and features of the new scheme and shows that The Society's work on this issue on behalf of its members continued, noting that *"The Society and our parliamentary supporters are actively seeking answers to a number of questions about the detail of the scheme."*

98. One of the criticisms made by W5739 is that The Society's *"had done too little too late when it came to advocating for safe therapies on behalf of haemophiliacs".* I would like to draw attention at this point to The Society's "Recombinant for All" campaign. This campaign was very active in advocating for safe therapies – and it still is to this day, with NHS England announcing in 2020 that the first recombinant treatment for adults living with von Willebrand disease would be made available. This was a significant development in access to treatment and shows the success of the campaign. Further, the fight to ensure people with von Willebrand disease have access to recombinant prophylaxis in the same way as people for haemophilia is something The Society continues to strive for; as well as recombinant products for those with rarer bleeding disorders.

99. A letter from Graham Barker (Director of Services and Development) to Members of The Society dated 22 August 1996 (Exhibit HCDO0000127_039) explains The Society's position on the use of genetically engineered recombinant clotting factors:

> *…The fear that other viruses might survive in plasma based products is the reason why the Society supports the use of recombinant clotting factors. History has shown us that blood borne viruses can cause devastation to the haemophilia community; we would be foolish to assume that this will not happen again. We now have the technology to prevent this happening again.*
>
> *Recombinant products would appear to provide the safest way forward. It is for this reason that the Society is arguing for the Government to provide sufficient funding for recombinant clotting factors rather than rely on individual health authorities to finance it out of their budgets. Secondly, we are asking the Government to eliminate, or least reduce the 17.5% VAT that is currently imposed on recombinant products.*

100. I would also like to draw the Inquiry's attention to a selection of documents that address the work of the "Recombinant for All" campaign:

a. Minutes of the Haemophilia Society Executive Committee meeting on 20 September 1995 under the heading "Blood Products Policy" at page 2 (Exhibit HSOC0029690_051);
b. Minutes of the Haemophilia Society Executive Committee meeting on 29 November 1995 under the heading "VAT on Recombinant Products at page 2 (Exhibit WITN6392273);
c. An article titled "VAT on Recombinant FVIII" at page 3 in the December 1995 edition of The Bulletin (Exhibit HSOC0022988) and an article titled "Haemophilia Society Blood Products Policy" at page 4 of the same document, which sets out The Society's revised policy towards blood products;
d. An article titled "Recombinant Factor VIII and product safety" at page 3 in the September 1996 edition of The Bulletin (Exhibit HSOC0023014);
e. The campaign update under the heading "Funding Recombinant factor VIII by Health Authorities" at page 12 of the first issue of the 1997 edition of The Bulletin (Exhibit HSOC0023017);
f. Minutes of the Board of Trustees Meeting dated 16 April 1997 under the heading "Services/Campaign Updates" at page 3 (Exhibit WITN6392274);
g. The Society's Minutes of the Board of Trustee Meeting on 24 July 1997 (Exhibit WITN6392275) under the heading "Recombinant Campaign" at page 5;
h. Minutes of the Trustee Meeting on 8 and 9 November 1997 under the heading "Recombinant Campaign" at page 11 (Exhibit HSOC0024167);
i. The campaign update under the heading "Recombinant factor VIII to be made available to all children under 16!" at page 1 of the first issue of the 1998 edition of The Bulletin (Exhibit HSOC0019596).
j. Letter from John Latimer to John Hutton, Minister of the Department of Health dated 16 April 2001 (Exhibit WITN6392276)

101. I also refer to the "Recombinant for all" campaign in first statement to the Inquiry [WITN6392001] in the section titled "Recombinant for all campaign" at paragraphs 282 to 284.

102. Turning back to further evidence in respect of the work done by The Society in respect of the HIV and Hepatitis C campaigns – the minutes of the Council meeting on 24

November 1996 (Exhibit HSOC0019925) provide the following update about The Society's Hepatitis campaign:

> *Mr Graham Barker updated the Council on the Hepatitis Campaign. He explained that the government had rejected the Society's claim for financial recompense. Despite this the campaign would still continue. A lobby of parliament was planned on 11 December 1996 followed by the handing in of a petition. Mr Barker appealed for all groups to support this event. He suggested that members contact their local MP for an appointment on the day. The Grand Committee room was booked with John Marshall MP and Alf Morris MP addressing the group.*

103. The Society's first 1997 edition of The Bulletin (Exhibit HSOC0023017) refers to the following information relating to Hepatitis C and HIV:
    a. An article on protease inhibitors for HIV (at page 9);
    b. An update on the Hepatitis C Handbook (at page 12);
    c. A report on the success of a Hepatitis C rally (at page 14)

104. In January 1998, The Society submitted a special briefing for members of Parliament. The submission titled "*Haemophilia and Hepatitis C: The case for financial recompense – Special Briefing for Members of Parliament*" (Exhibit DHSC0040895_009), includes:
    a. Information and background about people with haemophilia in the UK who were estimated at the time to have been infected with Hepatitis C through the use of contaminated blood clotting concentrates given as part of their NHS treatment (at page 1);
    b. Information and background about people with haemophilia who were infected with HIV through their NHS treatment with contaminated blood clotting concentrates prior to the introduction of viral inactivation procedures in 1986 (at page 1);
    c. Analysis of the similarities between HIV infection and Hepatitis C infection (at page 1);
    d. Discussion of the medical impact of Hepatitis C infection on the lives of people with haemophilia (at pages 1 to 2);
    e. Discussion of the social and economic impacts of Hepatitis C infection on the lives of people living with haemophilia (at page 2); and

f. A call for financial support to help alleviate the problems experienced by people infected with HIV and Hepatitis C (at page 3).

105. The Society completed various reports and tried to consider what steps could be taken to secure recompense for its members. An example of this can be seen in a Society Report dated March 1999, titled "*Haemophilia and hepatitis C – The Case For Recompense*" (Exhibit HSOC0026723). In this document, The Society makes an appeal to government for financial assistance for the 3,600 people that are infected with Hepatitis C and not co-infected with HIV:

> *At present no financial help has been made available to the people infected with HCV who are not co-infected with HIV, of whom there are some 3,600. Those people with haemophilia infected with HCV were infected at exactly the same time and by the same route as those infected with HIV, ie by contaminated blood products given as part of their NHS treatment prior to 1986. We believe that the moral responsibility accepted by the Government for those infected with HIV applies equally to those infected with HCV. It is irrelevant for these purposes whether or not they were receiving the best possible treatment at the time.*

106. In June 1999, The Society made a *"Submission to the Health Committee Inquiry into Procedures Related to Adverse Clinical Incidents and Outcomes in Medical Care"* (Exhibit HSOC0009369). In its submission, it made a number of recommendations, the first of which was a call for a public inquiry:

> *The UK Government should ensure that a full inquiry is conducted into the way in which patients with haemophilia were infected with viruses through contaminated blood, the impact this has had on their health, social and economic circumstances and that of their families, and whether adequate support has been provided. This inquiry should look carefully at how other countries such as Canada, Ireland and Italy have responded to the tragedy of contaminated* blood, and how similar approaches could be adopted in the UK.

107. At paragraph 227, of Simon Taylor's written statement [WITN4500001], Mr Taylor refers to Minutes of meetings of The Society's Board of Trustees on 30 November 2000 (Exhibit WITN4500026), 19 January 2001 (Exhibit WITN4500027) and 28 February 2001 (Exhibit WITN4500028) and explains that The Society moved forward

to employ a professional lobbying company to take over and conduct the campaign for compensation at an estimated cost of £115k for the first year, a selection process that Mr Taylor led.

108. The Society's summer 2001 edition of The Bulletin (Exhibit HSOC0023041) refers to the following information relating to Hepatitis C and HIV:

   a. Articles about the recombinant treatment shortage (at page 1 and page 12)
   b. An article announcing that The Society would be re-launching its campaign on behalf of those who were infected with HIV and hepatitis viruses through contaminated blood products (at page 2);
   c. An advertisement for a HIV and Hepatitis C co-infection seminar and for a weekend for young people living with haemophilia and HIV (at page 4);
   d. The results of a national survey of provision of care for patients with hepatitis and by haemophilia centres (at page 5);
   e. An article about a landmark court ruling about 114 people who were successful in their claim against the National Blood Authority for compensation for having contracted Hepatitis C through their NHS treatment (at page 6);
   f. An update about The Society's new "three stage" campaign strategy, which aimed to achieve:
      - *Recombinant for all, children and adults alike, throughout the UK to avoid the risks of future blood-borne infections.*
      - *A public inquiry in the tragedy of contaminated blood products that infected people with haemophilia with HIV and hepatitis viruses.*
      - *Financial recompense through a hardship fund for people with haemophilia infected with hepatitis C in addition to the financial assistance scheme established by Government in 1987 for those infected with HIV (the Macfarlane Trust).*

109 In March 2000, public health researchers Sarah Bond and Jennifer Roberts, prepared a report of a pilot study for The Society, "*The social and economic impact of Hepatitis C in* people *with Haemophilia*" (Exhibit HSOC0001075). The aims of the study were to test the feasibility of exploring the impact of Hepatitis C on those with haemophilia using a semi-structured interview and postal questionnaires to measure health status. The pilot study used a small non-random sample of individuals. The survey collected information on the type of haemophilia, the effect of Hepatitis C on the health status of cases, the management of the illness including components on the way individuals

were told about their Hepatitis C status, and the medical management and support given. Side effects of interferon were also documented and the reasons for the interruption or cancellation of the therapy noted. Some points to note were:

a. the manner of disclosure of Hepatitis C status was often *"far from satisfactory"* (see page 16);
b. following diagnosis, 40% of respondents said they were given no information (see page 17);
c. 85% of respondents had received no counselling (see page 19);
d. 35% of respondents had received interferon and/or ribavirin (see page 20).

110. In September 2001, The Society established the Hepatitis C Working Party. It comprised Matthias Kelly QC, Chairman of the working party and a QC specialising in medical negligence, a consultant actuary, several specialist haemophilia doctors with particular expertise in treatment of hepatitis, and the CEO of The Society at the time, Karin Pappenheim. Secretarial support was provided by the PR firm Weber Shandwick. The Hepatitis C Working Party was asked by The Society to devise costed proposals for a financial assistance fund to recognise the loss and suffering of people with haemophilia resulting from their infection with Hepatitis C.

111. In June 2002, the working party produced the "Report of the Hepatitis C Working Party to the Haemophilia Society" (Exhibit HSOC0005927). The report noted that as at 1 January 2000, the number of people living with haemophilia and Hepatitis C was 2,829. In the Executive Summary the report explained the working group's brief and their results:

> [4] *The brief for the working group was to develop proposals for a scheme which would provide financial assistance on the basis of medical need, and which would be relatively simple and swift to administer. The working group reviewed various schemes operating in the UK and abroad to find a suitable model. It was decided that the Canadian HCV Compensation Scheme provided the most suitable model and this was therefore used as the basis for our proposals. The working group also considered British common law principles of damages in adapting the Canadian model for the UK…*
>
> *[10] The estimated average cost of this scheme over a 10-year period is £52.26 million per year. By the inclusion or exclusion of various different elements of the scheme this total could vary significantly. For example, the ten year total*

> *would reduce by an amount in the order of £100+ million if only deaths from liver disease, rather than all deaths, were compensated.*

112. The minutes of the Campaign Supporters meeting dated 4 November 2005 (Exhibit HSOC0003014) records that the call for an independent public inquiry was discussed. It appears from the document that the group compiled an extensive list of actions and questions arising out of what appears to have been quite a full discussion under the heading "*Call for an independent public inquiry*". The list is set out in full below:

> ***<u>CALL FOR AN INDEPENDENT PUBLIC INQUIRY</u>***
>
> ***Justice = an explanation; protection for the future; a place in history; compensation; an apology***
>
> *Basis of call:*
>
> - *Knowledge that files had been destroyed*
> - *The question of whether product licences were available at the time*
> - *Scotland — no re-call of known contaminated products until 1991*
>
> ***Evidence resources:***
>
> - *Use Irish experience = invite Raymond Bradley (solicitor) to this group and locate English barrister*
> - *Use Canadian experience = Krever Report*
> - *"NHS caused illness" — current issue = 980K last year made ill*
> - *Charles Kennedy list = public exposed to 10 pathogens (BN)*
> - *HTVL1 [sic] payout — reference and driver*
> - *Freedom of Information Act*
> - *personal medical records (UKHCDO, NHS)*
> - *HIV — national significance = 20 yrs hereditary conditions — lifetime*
> - *Liverpool website (GL)*
> - *Lord Jenkin letters (AG)*
> - *Discrepancy "infected" v "informed" 1984-1994 solicitor Norfolk (MC)*
> - *Testing without consent*
> - *Scottish documentary*
> - *Charles Clarke letters asking for clarification of Freedom of Information Act and availability of files under 30 year rule dated January 2005 — reply received October 2005 but dated 7 March 2005*

• Justice Ognall direction (HL) original settlement — no-one was sent a copy of the report in 1990.
• Discrepancy between letter sent to AG and letter sent to MC (clarification required)
• Report to Crown Office from Chief Constable — need a copy
• Equivalent papers in England and Wales of Scottish BTS directors' minutes
• Medical Inspector's report (Robert McKie)
• Consumer Protection Act = 3 people March 2002 judgement, assumed earlier infection — cannot prove; products were in use (HL records show G1+ve 1st time 77999; Haemophilia Society holds these)
• US litigation = Criminal cases in Canada v pharmaceuticals, meeting /news imminent. If fails, may come back to UK for British people to sue through British courts. US cases have succeeded
• Scottish legal action — Margaret Unwin to meet counsel 15 November 2005
• Scottish Parliament — health committee receiving evidence early 2006
• Press resource — Mark Weaving of Myriad taken on
• Lord Owen Review (internal review by instigated by Hazel Blears in 2002 into why UK did not become self sufficient following Lord Owen's directive) — due soon, supposedly completed and with printers
• Barrister's opinion

To question:
• Why there was no Secretary of State for Health from June 1975 to 1976
• Lord Morris' use of the word "inadvertent"
• Lords' use of the word "compensation" where there has been no compensation

113. The Society's publication "H3" dated July 2006 (Exhibit HSOC0003689) provides further information on the front page in respect of the Hepatitis C and public inquiry campaigns under the title "Campaign developments":

> *It has been an extremely eventful first half of the year for the Society's campaign for a public inquiry and better recompense for hepatitis C infection. We have achieved extensive media coverage, a re-enthused campaigns group is meeting regularly and public and political pressure is mounting on the government to change its position…*

114. The same document goes on to list a chronological account of activities between December 2005 to June 2006 relating to The Society's campaigning efforts. Set out below are the specific references made to The Society's work in lobbying for a public inquiry:

> ***December*** *The Society issued a press release: "The Haemophilia Society is calling on the government to start the New Year with a commitment to hold a wide ranging public inquiry into the medical disasters of the 1970s and 1980s caused by NHS use of contaminated blood products."*
>
> ***...***
>
> ***18 April*** *The Society met with the All Party Parliamentary Group on Haemophilia and following a very constructive meeting the APPG, led by Michael Connarty MP and Lord Morris of Manchester, agreed to step up the campaign to ask the government for an independent public inquiry.*
>
> *...*
>
> ***April*** *The Society, via Philip Dolan, was again asked to give evidence to the Scottish health sub-committee. The result was that: "The committee has agreed to call for an independent public inquiry into the issues that have been before us until now. That will be communicated forthwith to the Minister for Health and Community Care."*

115. I have seen minutes of the Campaign Supporters meeting dated 4 November 2005 (Exhibit HSOC0003014). This document records that the call for an independent public inquiry was discussed. It appears from the document that the group made a list of actions and questions arising out of the discussion. The list is included under a heading "Justice" that it wanted "*an explanation; protection for the future; a place in history; compensation; an apology*".

116. The article on the front page of the first issue of 'HQ' in 2007 (Exhibit HSOC0023069) reports that The Society had been campaigning for a public inquiry since 1988 and provides information about the announcement of public inquiry set up in March 2007, chaired by Rt Hon Lord Peter Archer of Sandwell QC ("the Archer Inquiry"), looking into the events in the 1970s and early 1980s relating to the supply to patients of contaminated NHS blood and blood products.

117. Exhibit WITN1003002, provides a useful summary of additional articles and publications provided to this Inquiry. This document lists a significant number of

publications produced by The Society showing the wide breadth of issues that The Society engaged with, including HIV/AIDS and Hepatitis C. By way of example, I set out below the names of some of these publications, as they are described in the document:

- Sept, 1984 - Haemofact - AIDS No.4- Peter Kernoff. The Haemophilia Society
- Dec. 1984 - Haemofact - AIDS No.5- The Haemophilia Society
- May 1985 - Haemofact - AIDS No.7- World Hemophilia AIDS Centre. The Haemophilia Society
- Aug. 1985 - Haemofact AIDS No.8- The Haemophilia Society
- Sept. 1985 - Haemofact - AIDS No.9- The Story so Far. The Haemophilia Society
- Feb. 1985 AIDS and the Blood. A Practical Guide. Dr Peter Jones. H.Soc/THT
- Undated — (1988 ?) Guide to Benefits for people with HIV Infection. H.Soc
- Sept. 1993 — HCV medical Negligence Claims- Factsheet. H.Soc
- March 1995 — The Hepatitis C Campaign- Financial Recompense. H.Soc.
- Jan 1996 — Haemophilia and HCV Research Report. Mandy Cheetham H.Soc.
- Dec 1998 — HCV Camapign Update H.Soc
- July 1998 — Letter C Hodgson to Frank Dobson/ K. Pappenheim HCV Campaign. H.
- Aug 1999 - HCV Campaign Update (no.4) H.Soc
- Aug 1999 HIV and Haemophilia Youth Project. S. Fouch H.Soc.
- Nov. 1999. Alive and Kicking- guide to young adults with HCV. H.Soc.
- Nov. 1999 — Living Life to The Full-Guide for young Adults with HCV/HIV. H.Soc
- Nov 1999 — Being There. Guide to Parents with Children with HCV. H.Soc
- Dec, 1999 Response to Scottish Investigation into HCV infection via contaminated blood within the haemophilia community. H.Soc.
- Feb. 2000 — Hepatits C The Facts (information booklet pack) H.Soc
- March 2000- The Social and Economic Impact of HCV in people with haemophilia S Bond/J Roberts H.Soc
- March 2000 — Haemophilia and HCV The Campaign for Justice H.Soc
- June 2000 — HCV Campaign Update H.Soc
- Sept. 2000 — C Issues (no 16) H.Soc.
- Nov. 2000 — HCV Meeting the Challenge- booklet for adults on HCV H.Soc.
- Dec. 2000 — C Issues (no 17) H.Soc.
- Jan 2001 — Calling for Justice-Review of H.Soc Campaign. Politics Direct.

- 2001 — Carpet of Lillies Campiagn. (Press Release/ Fact Sheets/Public Inquiry) H.Soc
- March 2001 — C Issues (no 18) H.Soc.
- Sept. 2001 — HIV Youth Weekend Report. A Evans/ B Evans. H.Soc
- Sept. 2001 — C Issues (no 20) H.Soc.
- March 2002 — C Issues (no 21) H.Soc.
- June 2002— C Issues (no 23) H.Soc. Sept. 2002 C Issues (no 24) H.Soc.
- Dec. 2002 C Issues (no 25) H.Soc.
- March 2003 C Issues (no 26) H.Soc.
- May 2003 — Something For You. An Event for partners. Babs Evans. H.Soc
- June 2003 — C Issues (no 27) H.Soc.
- Sept. 2003 C Issues (no 28) H.Soc.

118. The long list of publications referred to above, coupled with the extensive (but certainly not exhaustive) actions described above, indicate to me that The Society has for the past 30 years, been continually engaged with the issue of people with bleeding disorders being infected with HIV and Hepatitis C. It is clear from the selection of references and documents set out above that The Society has been determined to campaign, advocate and fight to enable the voices of people with Hepatitis C or AIDS/HIV to be heard by Government decisions makers, the courts and the wider community. There is always more that can be done and perhaps some initiatives were less successful than had been hoped. The Society's campaigning style was not that of a single issue pressure group and clearly some feel and felt that The Society did not go in hard enough where Government was concerned. However, I see no evidence that The Society ever let up in pursuit of its goal of justice for its infected and affected members, or abandoned them and their struggles.

Topic 3: The Society and the Birchgrove Group

119. I now turn to comments made by W1122 and W5739 which refer to the Birchgrove Group and The Society's relationship with the group. W1122 believes the group was set up because a group of haemophiliacs and their families felt that no one (including The Society) was advocating, campaigning or fighting strongly enough to have their voices heard. From what I have seen and heard, this does seem to have been at least one reason why the Birchgrove Group was set up. It is possible that disillusionment

with The Society was a significant driver for those forming this group. I recognise that there were some people who felt that The Society did not do enough.

120. At paragraphs 53 to 54 of his statement to this Inquiry dated 18 January 2021 [WITN3429001], David Watters provides helpful background about the establishment of the Birchgrove Group:

> *[53] The Birchgrove Group was an independent group of people with haemophilia who had been infected with HIV. Originally established in Cardiff, it existed to provide mutual support for its members and also to campaign for improved care and financial recompense for those infected. As such, it was largely a 'single issue' group focussed on HIV, whereas the Society covered the whole range of haemophilia issues and represented the whole community of haemophilia, most of whom had not been infected with HIV.*
>
> *[54]. Because of their single focus, the Birchgrove Group could be frustrated at times that the Society was not doing more on HIV issues…*

121. W1122 describes the relationship between The Society and the Birchgrove Group as *"complicated"* and W5739 states that the Birchgrove Group's relationship with the Society was *"uneasy and that this was largely due to the Society shying away from the entire infected community".* I have seen a number of documents which show a relationship between The Society and the Birchgrove Group. There is no indication in these documents that The Society shied away from the infected community that the Birchgrove Group advocated for. However, I am aware that there was a split between people with different problems and different points of view:

- the Birchgrove Group represented the group of haemophiliacs who were co-infected with HIV and Hepatitis C;
- the Manor House Group represented the group of haemophiliacs with Hepatitis C;
- The Society represented the wide group of people who are affected by all bleeding disorders.
- The Society tried to maintain good relationships with all communities of people affected by a bleeding disorder, infected, affected and neither infected nor affected, but it struggled to be all things to all people and clearly disappointed

some. This position is illustrated well in an editorial by Dr David Evans published in the fourth issue of The Bulletin in 1998 (Exhibit HSOC0023024):

> *The Chairman and Vice-Chairman of the Manor House Group have both written about [REDACTED] appeal (in the Letters section of the last edition) for us all to work together as a united front. They both express the view that The Society is split into different groups and clearly feel that priorities of The Manor House Group differ from those of everyone else. In any Society there will always be people with different problems and different points of view; but we in the Haemophilia Society have to represent everyone's point of view. We are more likely to get what we want from the Government and others by speaking with one firm voice. The Manor House Group have told us what they need The Society to do; we have not yet achieved this, but we are and will continue to do our best for them and for all other members.*

122. The Birchgrove Group's relationship with The Society was indeed complex. As was, at times, The Society's relationship with the Manor House Group. In her statement to this Inquiry, Norma Guy dated 27 April 2021 [WITN5251001] who was a member of The Society's Executive Committee between 1991 to 1996 and also a member of the Manor House Group describes at paragraph 11 that she *"got the sense that, initially, the Haemophilia Society's Executive Committee saw the creation of the Manor House group as unnecessary and felt it was overriding the Haemophilia Society's efforts. The relationship between the two entities improved over time and they became more transparent and cooperative with each other."*

123. Karin Pappenheim, who was Chief Executive of The Society from March 1998 to April 2004 states in her witness statement dated 14 May 2021 [WITN4504001] about the Birchgrove and Manor House Groups:

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

> *HCV and HIV maintained communications links with the two groups. They did not operate in the same way as the local group branches. The Society provided funding to each of the two groups to support their work; details of which can be found in Board minutes of the time.*
>
> *[22] Relationships between those special interest groups and between each and the Society changed over time. Sometimes there would have been tensions and disagreements, although the Society worked hard to maintain communication with those groups and to be inclusive. There was a great deal of anger amongst members of both Manor House and Birchgrove because of the impact of infected blood; the co-infected HIV/HCV group had lost many members who had died. Bereavement and loss in such a small community was strongly felt, and very painful. A sense of injustice about the lack of accountability and responsibility by Government for the infection fuelled the anger, together with dissatisfaction with such financial assistance offered and the inequity of providing a scheme for those who were HIV co-infected and nothing similar to those infected with HCV. Such issues generated internal conflict, and disagreement.*
>
> *[23] Relations between the Birchgrove and Manor House two groups were strained when I joined in 1998 and there was a proposal discussed on my advice as CEO about arranging a formal mediation process. This was not agreed, and I am unsure whether any specific reasons were given by either Birchgrove or Manor House about why they refused mediation. I would say that relationships continued to be difficult to maintain during my tenure, and this was challenging to manage. In the end, it was not possible to continue. The Manor House Group eventually separated from the Society and continued as a separate group outside the charity. Some years later the Birchgrove Group also separated.*

124. It was a challenge for The Society to strike the right balance in representing the interests of its diverse membership – and things were not always smooth. However, it is important to acknowledge that The Society did deal with issues related to HIV and Hepatitis C infection head on. I set out below a further selection of documents that show The Society's work in this area – and which also show the relationship between The Society and the Birchgrove Group.

125. At page 3 of The Society's November 1993 edition of The Bulletin (Exhibit HSOC0022994), there is an article titled *"Self-help weekend"*, which describes the work of the Birchgrove Group and endorses a *"National Self Help Weekend"* held by the group. The article reports that one of the aims of the events was to *"set up a network of self-help groups across the UK, to be run by HIV positive people with haemophilia for HIV positive people with haemophilia, partners and families*". The article states that the event was attended by ninety people living and working directly with haemophilia and HIV. Among those attending were medical professionals from the field of haemophilia, HIV and AIDS representatives from the Macfarlane Trust, Haemophilia Society, Terrence Higgins Trust and the National Body Positive Group. The article comments positively on the event, stating that: *"The weekend was a great success and there are hopes that some more permanent developments will be formed as a result"*. The article also publishes a number of positive reviews from attendees at the event.

126. Minutes of the Executive Committee of The Society held on 7 May 1994 (Exhibit HSOC0000447) provide a further example of the relationship between The Society and the Birchgrove Group. At page 3 of this document, there is reference made to the HIV Task Group comprising of representatives from the Birchgrove Group and The Society's Executive Committee. This document records that *"Simon Taylor reported that the Birchgrove Group would like to hold a National Conference and the Society would support the Group in their proposed activities: Funding will be considered".* This suggests that The Society was willing to work with the Birchgrove Group in order to hold a national conference.

127. Minutes of the Executive Committee meeting on 7 July 1994 (Exhibit HSOC0024847) record that the first meeting of the HIV Task Group took place on 27 June 1994 *and* note that The Executive Committee endorsed the Services Committee decision to give the Birchgrove Group £7,500 for core funding and £2,500 for their conference.

128. Minutes of the Hepatitis Task Group dated 11 January 1995 also note that a request for core funding for the work of the Manor House Group was made. It was noted that The Society would consider this on receipt of a written proposal (Exhibit HSOC0003794).

129. Minutes of the National Birchgrove Steering Group on 5 to 6 March 1995 (Exhibit GLEW0000546) record a number of references to The Society (at paragraphs 3.1, 5.1, 6.1, 10.1 and 10.5) which show the working relationship between the organisations.

130. There is reference in the Minutes of The Society's Services Committee meeting on 12 April 1995 (Exhibit HSOC0023343) to a meeting that took place between The Society and the Birchgrove Group on 9 March 1995. Alan Tanner, Simon Taylor and Graham Barker met with four Birchgrove Group representatives. The Minutes report on what the Birchgrove Group needed from The Society in terms of demonstrating its commitment to people with haemophilia and HIV. The document records that *"a number of areas of broad agreement emerged"*. Certainly then, it seems that The Society was willing to adapt and meet expectations where it could:

> *Representatives from the Society (Alan Tanner, Simon Taylor and Graham Barker) met with 4 representatives of the Birchgrove Group (full details of the meeting to be circulated) to discuss a paper prepared by the Birchgrove Group. During the discussions a number of areas of broad agreement emerged. These included the need for the Society to demonstrate its commitment to people with haemophilia and HIV, the need to look at the Bulletin and its coverage of HIV, the need for improved communications between the Society, the Macfarlane Trust and the Birchgrove Group, the need to give the Birchgrove Group recognition within Council and the need for joint work between the Society and Birchgrove, and where appropriate, the Macfarlane Trust.*
>
> *The editor had met with representatives from the Birchgrove Group and agreed that future editions of the Bulletin would have a page devoted to HIV issues. The Society would work more closely with the Birchgrove Group on its conferences. It would also consider how to improve its information and advice resources, and the referral of appropriate calls to the Birchgrove Group. It was also agreed that the Macfarlane Trust, the Birchgrove Group and the Society would produce a newsletter on information resources. The editors would be [REDACTED], Simon Taylor, and [REDACTED]. Graham Barker reported that the Society was co-operating with the Birchgrove Group on commissioning a consultant to look at the needs of long term survivors and also ways of meeting their needs. The consultant would report on how best to improve access to information and services for HIV positive members and their families.*

> *[REDACTED] expressed the view that the Society should produce a charter outlining its aims and current activities relating to all areas of work, so that members would know what to expect from the Society, and this was agreed to. Andy Cowe raised the issue of the constitutional relationship between the Birchgrove Group and the Society. It was agreed that the Constitutional Working Party should meet with representatives of the Birchgrove Group and the Manor House Group as a matter of urgency.*

131. Minutes of The Society's Services Committee dated 12 April 1995 (Exhibit HSOC0023343) record that a member of the Birchgrove Group was welcomed to the meeting and would join future Services Committee meetings. It was noted that Simon Taylor would attend future meetings of the Birchgrove Steering group. The same minute notes that the Manor House Group has raised the question of funding for their activities (but had not indicated any specific figure). The minutes record that The Society would consider any formal proposal for funding from the Manor House Group. The issue of incorporating the Manor House Group into The Society's constitution was also raised; it was noted for discussion at a Manor House Group meeting on 23 April 1995. In the same minutes, it was also reported that Mandy Cheetham had been appointed as The Society's Hepatitis Worker and that she would attend future meetings of the Manor House Group.

132. Minutes of The Society's Executive Committee on 2 May 1995 (Exhibit WITN6392277) record that meetings would be arranged with the Manor House Group and Birchgrove Group to discuss their relationship with The Society in the context of its constitutional review. The minutes note that *"[Simon] Taylor, as a member of the Birchgrove Steering group, agreed to take soundings from the Birchgrove Group, and Mr Cowe agreed to continue his dialogue with the Manor House Group. Mr Cowe reported that the next steps are to arrange the above meetings with the special interest groups, and for the Paisner & Co to draft out the new Memorandum and Articles. These would be presented at an EGM towards the end of this year with a view to implementing the new system by the AGM in 1996."*

133. The same document also reports on The Society's activities relating to the Hepatitis C Campaign, including:

    a. a press release sent to all MPs inviting them to support the campaign;
    b. a letter sent to members asking them to write to their local MP;

c. a meeting between John Marshall MP, Sir Geoffrey Johnson-Smith and Gerald Malone, Minister of the State for Health, to present The Society's case;

d. a written reply from Tom Sackville, Parliamentary Under Secretary for Health sent to all MPs who wrote to the Secretary of State for Health about haemophilia and hepatitis C. The letter was about treatment and research;

e. attendance by 20 MPs at an All-Party meeting held at the House of Commons. The minute records that "After a short presentation by the Chairman the MPs discussed how they could support the campaign".

134. In various editions of The Society's publication The Bulletin there is a "Red Ribbon Page", which provides details of the activities being carried out by the Birchgrove Group. The Society's June 1995 edition of The Bulletin (Exhibit HSOC0022986) provides an example of "The Red Ribbon Page". At page 6, The Society publicly sets out its intentions for how they intended to demonstrate their support for people with haemophilia and HIV, including making specific mention of its support for the Birchgrove Group:

> *The Society will support self help initiatives for people with haemophilia and HIV and their families and seek to gain access to services provided by other agencies that are of benefit to people with haemophilia and HIV.*
>
> *To achieve these objectives the Society will endeavour to do the following:-*
>
> - *encourage the Birchgrove Group to continue its work in developing regional networks of self help by providing practical and financial support; work with other HIV agencies to discuss common concerns and if appropriate share platforms with them;*
> - *work with haemophilia centres and individual staff to ensure that funding for HIV work is maintained and encourage their support for local self help initiatives as part of a national network;*
> - *encourage the Society's local Groups to become more "HIV friendly" and provide more support to those who have haemophilia and HIV, and their families;*
> - *Give greater prominence to HIV issues in the Society's publications*

135. On the same page, The Society publication promotes a number of *"Plans in the Pipeline"*, including a "*joint Birchgrove/Society weekend for people affected by HIV"*. As detailed above, the same issue refers to information relating to Hepatitis C and HIV.

136. The Society's Haemophilia and Hepatitis C Research Report by Mandy Cheetham (Exhibit HSOC0002726_001) contains the findings of a six-month research project carried out by The Society between June and December 1995. The remit of the research project was to "*a) examine the support needs people with haemophilia and hepatitis C, their partners and families; and b) to look in to existing support services available to people with haemophilia and hepatitis C*". The report is based on responses in 101 written questionnaires, including 39 which were completed during one-to-one interviews conducted over the phone or face-to-face. At page 10, paragraph 4.4 of this report, the Birchgrove Group and Manor House are referred to as a source of peer support for people affect by Hepatitis C:

> *4.4 PEER SUPPORT The development of Peer Support Services was identified as important. Many people felt that others affected by hepatitis C would be a better source of support than well-meaning professionals. The establishment of a "support network" for groups or individuals affected by hepatitis C and the specific ways in which this could be set up present an area for further investigation. Consultation with the Manor House Group and Birchgrove Group, both of whom have extensive experience, should form part of this process.*
>
> *The Haemophilia Society, its local group network and Centres were seen as having a role in putting people in touch with others similarly affected. Suggestions included bringing people together at local level, as well as relying on centres to be a source of support or point of contact.*

137. Minutes of a meeting of The Society's Executive Committee on 13/14 October 1995 (Exhibit HSOC0029690_052) record at page 7 discussions regarding the constitutional review and the *integration* of the Birchgrove and Manor House Groups into The Society:

> *Mr Cowe reported on the Birchgrove and Manor House groups integration into the Society. The negotiations are making good progress, but had raised three issues. Firstly it was recommended that the Society adopt a policy in the guidelines where they aspire to having 60% of the Executive Committee being composed of people with haemophilia. This was accepted by the Executive. Secondly, the Birchgrove group felt that the Society ought to have an equal*

> *opportunities policy. The Executive were satisfied that they do. Finally the group were very concerned about confidentiality issues. The Society would seek clarification of the legal requirements of the Data Protection Act*
>
> *The solicitors were concerned about 'mini Birchgroves' almost becoming charities in their own right. Mr Cowe presented two models of organisation structure proposed by the solicitors to solve this problem. The Executive preferred the second model which involved three consultative groups reporting to the Executive. The Birchgrove group also wanted its own steering committee because of its specialised nature. The Birchgrove and Manor House groups have taken away the proposals and will discuss them before submitting revised proposals for consideration by the solicitors.*
>
> *Mr Pepper commented that he felt the rules regarding group structure were too rigid and would not allow for a diversity of groups. Ms Archer replied that the rules are simply a skeletal framework which is a legal requirement, and would not restrict group activities.*

138. The December 1995 edition of The Bulletin (Exhibit HSOC0022988), provides a further *example* of "The Red Ribbon Page" on page 6. This page includes an article that addresses the long term effects of HIV on individuals who are long term survivors of the virus. At the end of the article, there is a note that this article was *"submitted to the Bulletin by members of the Birchgrove Group".* The same edition of The Bulletin also includes a positive review of a "Complementary Therapy" weekend that was "successfully held" by the Birchgrove Group on 13 and 14 October 1995 at page 5. The issue also provides information relating to Hepatitis C and HIV as detailed at paragraph 95 above.

139. A document dated 2 January 1996 (Exhibit HSOC0000237) shows The Society setting up a "brainstorming meeting" on the Hepatitis Campaign. The approach appears inclusive and The Society was looking to invite representatives of Manor House and Birchgrove, amongst others. Similarly, a letter dated 5 January 1996 from Graham Barker (The Society's Director of Services) to David Evans (Exhibit WITN6392278) addresses the same "brainstorming meeting" ahead of engagement with Minister for Health, John Horam who had *"indicated that he would be willing to discuss specific proposals from the Society in relation to [The Society's] hepatitis campaign.* Mr Barker wrote that the purpose of the meeting would be to *"a) discuss a range of proposals*

(including figures) that could be presented as a package for consideration by the Minister and b) see if there is a consensus on what kind of settlement might be acceptable to the membership". Mr Barker noted in his letter, *"I have invited a range of members of the Society including members of the Executive, members of the Manor House Group and Council members. It is very important the full range of views are expressed at the meeting…"*

140. The Society's first edition of The Bulletin in 1996 (Exhibit HSOC0023012) includes at page 13 a profile of GRO-A, who was an Executive Committee member and a member of the Birchgrove Group's steering group, when it was first set up on July 1990. GRO-A is quoted in the article as saying, *"At first there wasn't much communication between Birchgrove and The Society… But both were keen to build bridges and now work closely together, with the activities of the two organisations complementing each other."*

141. A further example of the "Red Ribbon Page" can be found in The Society's July 1996 *edition* of The Bulletin (Exhibit HSOC0023013). At page 6, there is an article about experiencing discrimination as someone living with HIV.

142. Minutes of the Board of Trustees weekend meeting held on 20 to 21 September 1996 (Exhibit HSOC0029689_009) record that GRO-A presented a proposal to the Board of Trustees on appointing a HIV worker to provide support and advice to people with haemophilia and HIV, their partners and families (in which research conducted by the Birchgrove group was referenced). The minutes record that following discussion, the Trustees approved the appointment of a HIV worker and asked the HIV task group to formulate a job description and the work with the Chief Executive to produce a financial plan.

143. The Birchgrove Group's thirteenth issue of the magazine 'The Birchgrove' (Exhibit WITN2384014) reported on appointment of the HIV Development Worker, Stephen Fouch from January 1997. At page 13, the article states:

> *The HIV worker at [T]he Society is there to fulfil a number of roles. One aspect is to provide information and support to individual Society and Birchgrove members, with enquiries and concerns about HIV related issues. This can include concerns over treatment, access to other services, or general information/advice (enquiries over benefits, housing issues and so on should still usually be directed towards the Macfarlane Trust).*

> *In addition, the HIV worker still acts as a link and liaison point for Birchgrove and The Haemophilia Society with other HIV organisations at every level. The HIV worker has a role in interpreting the needs of those with HIV and Haemophilia groups such as the All Parliamentary Group on HIV and AIDS, and non-governmental organisations such as the National AIDS Trust. The HIV Worker will also act as a link and advocate for people living with HIV and Haemophilia and HIV Treatment Centres, social services departments and other voluntary organisation across the United Kingdom. The Society aims to keep the issues and needs of those living with Haemophilia and HIV at the forefront of the minds of those making decisions about HIV treatment and service policies, and those actually providing both HIV and Haemophilia care.*
>
> *The HIV Worker is there as a resource to all Birchgrove members and others affected by HIV and Haemophilia up and down the country. This marks the beginning of a more active involvement by [T]he Society in the needs of all those living with Haemophilia and HIV.*

144. Despite taking these positive steps to support people with HIV, the same issue of 'The Birchgrove' includes an open letter on the front page that is critical of The Society in addressing the needs of people with HIV and haemophilia; and those co-infected with HIV/Hepatitis C.

145. The Society's first edition of The Bulletin in 1997 (Exhibit HSOC0023017) provides a further example of "The Red Ribbon Page". Page 11 announces the success of the Birchgrove Wales in their bid to the National Charities Board. It also refers to the following information relating to Hepatitis C and HIV:
    a. An article on protease inhibitors for HIV (at page 9);
    b. An update on the Hepatitis C Handbook (at page 12);
    c. A report on the success of a Hepatitis C rally (at page 14)

146. Minutes of a Trustee meeting on 7 November 1997 (Exhibit HSOC0024167) record that representatives of the Manor House Group were invited into the meeting. The minutes note that the Trustees were thanked on behalf of the Manor House Group for giving them to put forward their point of view and that *"the Manor House Group had no intention of working against the goodwill of the Haemophilia Society"*. The Group's reason for attending the meeting included to express concerns about The Society's

Chief Executive and The Society's work related to Hepatitis C. Although a number of concerns were raised the document also records that the issue *of "how the Manor House Group and the Haemophilia Society could work better together"* was also raised.

147. A letter dated 22 January 1998 was sent from the Chair of Birchgrove National to the Chair of The Society (Exhibit HSOC0012492). In this letter, the Chair of the Birchgrove Group offers his group's support to The Society so as to "*present a unified front*" in their dealings with the Department of Health at the time:

> *… we would like to offer our support to the society in your dealings with representatives of the Department of Health relating to HCV. We feel we could present a unified front in this process and our motivation would not solely be financial gain, but would be to help those who, like ourselves, have been dealt a bad hand in the form of infection through factor VIII infusion.*

148. In the same letter, the Chair of Birchgrove National states they have *"no confidence"* in the Manor House Group *"in their dealings either with the Haemophilia Society or Department of Health representatives with reference to HCV needs or the recompense claim"*. It appears that there was a complicated relationship between the Birchgrove Group and the Manor House Group, as well as The Society.

149. Notes from a campaign meeting held on 11 September 2001 (Exhibit HSOC0000445) refer to an *"apparent split"* between The Society and other groups. The document records Dave Tonkin, Chair of the Manor House Group, saying:

> *.. that the special interest groups of the Society had never had a disagreement amongst themselves they just had a lack of trust for the Society. He said that when the task groups were disbanded in 1998/9 the members' input into campaign activities was brought to an end and ignored. He said that the members of the Society should have been balloted on their ideas for a way forward and that local and special interest groups had never had a chance to express how they felt and this had driven the wedge. He said that the Society had a small membership anyway — 300 haemophiliacs recognised by government and parliament and if there is anything to come from government it won't be through the Society that this is received but through the particular groups. He said the campaign was not about money as Manor House group*

> *was doing it on a shoestring and the task groups should be brought back so that people with haemophilia can be involved.*

150. The Inquiry has heard about disaffection with the group structure of The Society, with a sense of unfairness that groups had to send money they raised to the centre. There was clearly a perception that The Society was not listening to some with special interests and was insufficiently democratic. For a small charity with a large and diverse membership, getting representative engagement from members is always a challenge, as is identifying how best to allocate resources. No doubt The Society did not always get it right. It may be that the dispute was more about the means than the end. The goals of public identification of the truth of what happened to the haemophilia community, public accountability, and financial fairness for those infected and affected seem to have been shared then and now. This is a group of people many of whom felt that they had been avoidably infected by the State; lied to and, in the case of the waiver, manipulated; and then the State had covered up the truth of what happened, required them to beg for money that had been allocated to them; and withheld a public inquiry until many of those who could have told the truth had died. It would be unsurprising if, within this damaged and struggling community, loss of hope led to internal division and blame casting. It is clear from those statements to which I am responding that at times, The Society did not always conduct the fight for justice in the way that all of the community wanted. However, its fight for justice was constant and there is no basis for the perception that it was in the pocket of Government.

151. W1122 also makes criticisms about The Society regarding funding for the Birchgrove Group. W1122 states that they understood The Society received funding from central government to advocate on HIV and AIDS related issues. W1122 believes that The Society did not want to be seen to be advocating on these issues and, instead, wanted to distance itself from infected haemophiliacs. Furthermore, the witness states that The Society transferred the funds it received from the Government to the Birchgrove Group so that the Birchgrove Group could do this work.

152. In relation to W1122's comments about The Society's campaigning and advocacy efforts on behalf of people infected with AIDS and HIV, I refer the Inquiry to my comments earlier in this section. In relation to W1122's comments about funding for the Birchgrove Group, I have read the second written statement of Robert James to this Inquiry dated 6 November 2020 [WITN1004002], who was previously Chair of the

Birchgrove Group. I wish to refer the Inquiry to paragraph 19 of his statement where Mr James discusses funding:

> *The organisation initially raised its own funds to provide for residential support. We later received funding to employ some support workers in Wales and to produce a free quarterly newsletter. Later when the Macfarlane Trust (MFT) changed their policy and decided that residential support weekends were within its funding remit, Birchgrove discontinued running the residential support events and instead supported the organisation of them.*

153. Mr James' comments do not seem to sit in line with W1122's comments.

154. The minutes of the first meeting of the HIV Task Group on 27 June 1994 (Exhibit HSOC0023418) record that:

> GRO-A *specified that the Birchgrove Group was requesting 'core funding' to facilitate its activities that would match the amount provided to the group by the National AIDS Trust (£10,000). Simon Taylor stated that the Society would see what funds were available and would seek to include support for the Birchgrove Group when preparing the budget for 1995. It was agreed that members of the Birchgrove Group would draw up a list of proposals outlining what the funds would be spent on and the activities that would be undertaken. This would then be presented to the Services Committee. Graham Barker stated that it would be necessary for the Birchgrove group to provide the Society with information pertaining to the allocation of National AIDS Trust funds and prospective Society funds.* GRO-A *also requested that the Birchgrove Group be allowed to use the Society's name when approaching funders for a national worker; and that the Society would work co-operatively with any worker who was attached to another agency working behalf of the Birchgrove Group as part of its work on HIV.*

155. The report of a Services Committee meeting dated 30 June 1994 (Exhibit HSOC0023357) records at page 2 that on 27 June 1994, at the first meeting of the HIV Task Group, that the meeting made a number of recommendations for consideration by the Services and Executive Committee regarding support for the Birchgrove Group's activities.

> *Firstly, in relation to the development of a regional self help network:*
>
> > *a) the Society would allow the Birchgrove Group to use the Society's name when seeking funding for a worker*
> >
> > *…*
> >
> > *d) the Society would give financial support to the Birchgrove Group to develop their work (ie core funding). The National AIDS Trust have given £10,000; matching funding was requested. The Birchgrove Group agreed to provide details of how this money would be spent… The Society has this year budgeted to give £10,000 to Birchgrove Group*
> >
> > *e) the Society would seek to set aside additional funding next year to provide core funding to the Birchgrove Group.*

156. Contrary to W1122's comments, these references indicate to me that The Society was neither trying to distance itself from the Birchgrove Group (in fact, The Society was willing to allow the Birchgrove Group to use its name when seeking funding for a worker), nor is there any indication that The Society transferred any funds from government because it did not want to be seen to be advocating on AIDS and HIV related issues. In fact, this funding was requested by the Birchgrove Group itself. Further, I echo Mr Watters' observations that based on the minutes of the Services Committee dated 30 June 1994, The Society could be said to give *"considerable financial, logistical and other support to the Group and there are frequent references to the Group and its work in the Bulletin."*

157. Also related to the issue of funding for the Birchgrove group, W5739 states they believe that The Society paid for the Birchgrove Group's newsletter because the Society did not want to include the information in its own publications. The witness offers two explanations for this: firstly, because any mention of HIV in a Society publication would likely be disapproved of by the pharmaceutical industry. Secondly, the witness believes he heard that the mention of infections might upset newly diagnosed haemophiliacs.

158. In response, I refer the Inquiry to The Society's publications that mention HIV and Hepatitis C infection above. It is my understanding that donations received by The Society from pharmaceutical companies would need to have been made under contracts in line with the Code of Practice issued by the Association of the British Pharmaceutical Industry. From the evidence the Inquiry has heard to date there is no basis for the suggestion that The Society censored mention of HIV in its publications

in order not to offend pharma. And the wealth of HIV publications suggests that this was simply not an issue.

159. It is clear from the evidence of a number of witnesses to this Inquiry that The Society did not refrain from publishing articles or publications in exchange for or with the expectation of receiving financial contribution or any other benefits. See for example paragraph 136 of Simon Taylor's witness statement dated 22 April 2021 [WITN4500001]; and paragraph 241 of Karin Pappenheim's witness statement dated 14 May 2021 [WITN4504001]. Also, as referred to at paragraph 106 above, in 1999, The Society produced an important document for the Health Committee Inquiry into Procedures Related to Adverse Clinical Incidents and Outcomes in Medical Care calling for a public inquiry. Calling for a public inquiry into past events would be counter-productive for an organisation whose aim was to distance itself from the past.

Topic 4: The Society and the UKHCDO

160. W1122 and W5739 refer to The Society's relationships with and the information given to its members based on guidance from Haemophilia Centre Directors (now known as the "UKHCDO"). W1122 and W5739 criticise The Society for not challenging the advice given by the UKHCDO and *"parroted its advice about continuing to take whatever was prescribed by haemophilia centres"*.

161. Historically, The Society relied heavily on its Medical Advisory Panel and the Inquiry has heard significant evidence in respect of how The Society sought the Medical Advisory Panel's advice and relayed such advice and information to its members. Due to the limited number of haemophilia clinicians in the UK, The Society's options in respect of obtaining assistance was limited. Also, most members of The Society's Medical Advisory Panel were members of the UKHCDO.

162. The Society sought information and answers to members' questions from clinicians and scientists who were experts in their fields. Many fitting that description were members of the UKHCDO. As the Inquiry has heard, on the issue of whether people with haemophilia should continue to take Factor VIII imported from the US when AIDS was first heard of, the UKHCDO spoke with one voice. I have already mentioned The Society's document of 4 May 1983 in which it reproduced the advice of Professor Bloom, who was considered an authoritative expert by The Society (and the Government and others), at the time and whose recommendation appears to have

been shared by all other clinicians who have provided evidence to the Inquiry. The Society will have more to say about this document, and subsequent publications which talked about the comparative safety of imported Factor VIII it in its final submissions.

163. In my first statement to the Inquiry [WITN6392001], I address the topic of The Society and its engagement with clinicians at section 3. Set out in my first statement are a number of historical documents which may assist the Inquiry in relation to ascertaining the role The Society played in providing medical advice to its members. In the remainder of this section, I set out a number of documents which may assist in responding to the criticisms made against The Society.

164. There is a memo from Graham Barker to the Hepatitis Project Team dated 30 October 1991 regarding comments from several doctors (Exhibit WITN6392279). This provides an example of how The Society sought the opinions of clinicians in order to assist with its work.

165. David Watters comments on the relationship between The Society and the UKHCDO at paragraph 72 of his statement dated 18 January 2021 [WITN3429001]:

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

166. David Watters goes on to describe the context within which The Society received advice from the UKHCDO at paragraph 237 of his statement:

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

167. At paragraph 238 of his statement, David Watters paints a picture that is at odds with W5739's comment that *"the Society doubled down on its relationship with UKHCDO and parroted its advice about continuing to take whatever was prescribed by haemophilia centres"*:

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

168. I also wish to refer to and acknowledge the powerful concluding comments that David Watters makes at paragraph 240 of his statement:

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

169 I also wish to note a letter dated 27 September 2006 from Dr CRM Hay (Chairman of the UKHCDO) to Margaret Unwin (who was Chief Executive of The Society at the time) (Exhibit HSOC0001265) which illustrates that in circumstances where the views of The Society and the UKHCDO did not align, The Society has not always followed the UKHCDO. The letter was sent in response to The Society's request for the UKHCDO to comment on the Department of Health's report entitled, "Self sufficiency in blood products in England and Wales – A Chronology from 1973 – 1991". In the letter, Dr

Hay states the UKHCDO's *"collective view that a public enquiry [sic] into this matter is not in the patients' best interests and is likely to harm rather than enhance patient care".* Despite the UKHCDO's views to the contrary, The Society continued its campaign for a public inquiry well beyond this date.

170. On 27 March 2017, the Board of Trustees issued a statement on behalf of The Society in which The Society accepted that its actions and statements at the time, while well intentioned and based on expert advice, have subsequently been shown to be damaging to the community and false. For this, we apologised unreservedly. (Exhibit WITN1056184).

171. In this statement The Society wrote:

> *We want a full public inquiry under the inquiries act as only this could compel witnesses and would shed light on concerns such as:*
>
> - *the inappropriate use of known infected treatments on previously untreated patients*
> - *why and how British self-sufficiency in blood products was never achieved*
> - *why tests to identify infected blood donations were not implemented sooner*
> - *when and to what extent the UKHCDO, The Haemophilia Society, the Department of Health and the NHS held and were aware of information on risks and tests for infection with blood borne viruses*
> - *why potential methods to heat treat blood products were not fully investigated and implemented sooner*
>
> *To facilitate this we want [sic] a full and open disclosure of all information held by the Government, or elsewhere, relating to the sourcing, manufacture, procurement, licensing and NHS treatment with contaminated blood and blood products. However, an inquiry must not distract from or delay the implementation of an improved support scheme.*

172. In their statement, W1122 also says that there was "*the sense that the Society was partisan against haemophiliacs in any attempts to go to court to get some form of justice*". The witness then raises the Society sharing its legal advice on the 1990/1 litigation with the UKHCDO, and claims that the Society, through the 1990s, distanced itself from infected haemophiliacs. At paragraph 166 of his statement dated 18 January 2021 [WITN3429001], David Watters responds to a question by the Inquiry as to why

on 16 February 1987, he sent counsel's opinion on the prospects of success of the litigation to members of the Medical Advisory Panel. Mr Watters responded:

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

173. Mr Watters provides some further context about The Society's relationship to the HIV litigation at paragraphs 164 and 168 of his statement:

> *[164] As I recall it, The Society's role in the HIV litigation was minimal. We provided a list of potential solicitors to those members who wanted to follow such action. We attempted to identify solicitors spread around the country.*
>
> *…*
>
> *[168] Throughout the entire litigation we had been at pains to show people that their relationship in relation to this was with their solicitors, and not with The Haemophilia Society (as referred to above). We were without function in relation to the litigation, as such, when people were offered settlement that had been negotiated by their lawyers, they were told that they should follow the advice of lawyers, and we could not become involved in that. On recollection, the work that had been undertaken by The Society to guide people towards accepting the settlement was simply to obtain the correct legal advice. The Society could not hold a view as to whether a settlement was fair and reasonable. It was up to individuals to hold that view.*

174. Simon Taylor also explained during his oral evidence on 26 May 2021 why The Society chose to share the fact that it had received negative legal advice with the Government. At page 36 an onwards, Simon Taylor states "*The Government's position that we should pursue a litigation approach, frankly, was an abdication of their responsibilities and it was, to some extent, a sort of 'Get out of jail' card. Because they knew very well that people were dying, and that, by the time the litigation was complete, there would be many, many deaths, and that wasn't going to be an appropriate solution. So it was important for us to say to the Government: what you are suggesting is not reasonable or realistic in providing support for people who urgently need it now*". Therefore, it appears that The Society's view at the time was to try and some form of monetary fund

for those infected and affected as soon as possible without the need for lengthy litigation.

175. A Briefing paper on Haemophilia and AIDS prepared by The Society dated October 1989 (Exhibit LDOW0000295) explains that a reason why The Society did not pursue litigation was that Legal Aid was only available to some infected members – others would have to pay legal fees privately and could not afford it. The Society therefore focussed its efforts on campaigning for speedy financial relief for the greatest possible number, in the context of many being infected or affected by a rapidly fatal illness for which there was no cure.

176. The Society has never been party to any criminal or civil litigation in relation to AIDS, Hepatitis B, Hepatitis C and/or vCJD in blood and/or blood products. The documents I have been shown illustrate that historically, The Society was aware that not all infected members qualified for Legal Aid and it focussed its efforts on campaigning for speedy financial relief for the greatest possible number, in the context of many being infected or affected by a rapidly fatal illness for which there was no cure. It did so by exerting public, moral pressure on the government, rather than by litigating. In my first statement to the Inquiry [WITN6392001], I set out a number of documents which might assist the Inquiry's understanding in this regard in section 1, question 7, at pages 43 to 52.

Topic 5: The Society and the pharmaceutical industry

177. W1122 states that The Society had close ties to the pharmaceutical industry, who gave donations, provided branded promotional goods and sponsored trips to conferences. The witness states that they saw how close those ties were and how much The Society relied upon the pharmaceutical industry for funding when they became a trustee of The Society. The witness states that the 2015 funding report from the minutes of The Society's board meeting in February 2015 gave them this awareness.

178. The Minutes of The Society's Board of Trustees' meeting on 4 February 2015. (Exhibit HSOC0029441_003) record that fundraising was discussed at the meeting and that a Fundraising Report for February 2015 is attached at Appendix B (Exhibit HSOC0029441_005).

179. At the beginning of the report, it states:

> *As predicted at our last Board Meeting, Q3 of our financial year was very successful and saw increases in Christmas activity as well as continued positive messaging and financial support from our Pharmaceutical partners. Bayer, CLS Behring, Pfizer and Octapharma all increased their giving bringing our YTD total to a very satisfying £87,668 up on target, with one more fundraising quarter still to be undertaken of the financial year.*

180. The report later sets out the following sums on the last page:

> ***Income to 31 December 2014***
> *Income - £514,344.53 (153%)*
> *Income target - £335,600.00*
>
> ***Community Events & Challenges***
> *Justgiving — £61,661.75*
> *Virgin Money Giving - £31,900.16*
> *YTD - £93,561.91*
>
> ***Annual Appeal & Christmas***
> *The total target for the Annual Appeal, Christmas cards and Annual Draw was £24,000. The total income showed a strong 8% increase on the target at £26,044.48…*
>
> ***Pharmaceuticals***
> *Baxter - £20,600*
> *Bayer - £74,500*
> *CLS Behring - £65,000*
> *Pfizer - £25,567.6*
> *Sobi - £5,500*
> *Octapharma - £5000*
> *TYD - £196,167.60 (181%)*
> *Target - £108,500.00*
>
> *This bodes well for a projected income of £220,000 for the next financial year.*

181. This document shows that the year-to-date giving received from pharmaceutical companies was £196,167.60 – out of a total income of £514,344.53 (which equates to approximately 38%).

182. I address the topic of The Society's relationship with pharmaceutical companies in section 4 of my first statement to the Inquiry [WITN6392001]. I also address the topic of The Society's funding overall in section 1, question 4(c) of the same statement.

183. As mentioned in my first statement to the Inquiry, at present, The Society receives funding from a range of organisations and members of our community, including through fundraising by members and volunteers; grant and trust income; corporate income; and legacy income. Like many charities working in the healthcare sector, including haemophilia societies across the UK and Europe and the EHC and WFH, a proportion of that funding comes from pharmaceutical companies. This funding helps support projects such as the Newly Diagnosed Weekends, Talking Red, and Youth Ambassador projects.

184. Without this funding, it would be impossible for us to run many of these programmes which members tell us offer essential support to them. We understand that many people within our community are concerned by any link to pharmaceutical companies, which is why it is very important to The Society that our sources of funding are clear.

185. There are strict guidelines relating to donations from pharmaceutical companies to health organisations. Companies must respect the independence of the project and organisation to which they have donated and are not allowed to influence any of its written material.

186. The Society decides which projects it wants to deliver, based on feedback from members and then approaches companies that it feels are best placed to offer financial support. Often, more than one company will fund a project. At all times The Society maintains its independence. The funding company cannot dictate how a project is run or have any input in its content or outcome.

187. As per clause 27 of the 2019 Code of Practice for the Pharmaceutical Industry published by the Prescription Medicines Code of Practice Authority ("PMCPA") established by the Association of the British Pharmaceutical Industry ("ABPI") ("2019 ABPI code"), all pharmaceutical companies must declare their sponsorship of "patient

organisations", which is how The Society is classed under the code. It must be made clear which company is supporting each programme. The details of funding by individual project can be found on the individual company websites as per clause 27.7. This must be published once a year, although some companies produce this information twice a year.

188. It is my understanding that other Haemophilia Societies in the UK also receive donations from pharmaceutical companies. This Inquiry has heard that other societies have contacted various pharmaceutical companies asking for contributions towards events. Donations received by any charity from pharmaceutical companies would need to have been made under contracts in line with the Code of Practice issued by the ABPI. The ABPI rules cannot insist on projects being funded solely by one pharmaceutical company. Wherever possible, we endeavour to have projects funded jointly to avoid suggestions of bias. In addition, trustees of all charities have a duty to demonstrate to the Charity Commission that they have acted with reasonable care and skill in the best interests of the charity when choosing to accept or reject a donation. The Institute of Fundraising also sets out some good practice guidelines on the acceptance or refusal of donations. Trustees have a duty to act in the best interests of the charity and The Society has always, and continues to, rely on donations to ensure that it can continue with its work.

189. It is my understanding that the EHC also receives donations from pharmaceutical companies. The EHC's 2002 annual report (Exhibit WITN6392280) notes at page 8 that the following companies had supported the EHC's work in the form of core funding or by sponsoring the EHC's members' conference: Biotest Pharma GMBH; Baxter Hyland Immuno; Bayer; Shanghai RAAS; Alpha Therapeutic; and Octapharma AB.

190. Individual trustees of The Society may also receive funding from pharmaceutical companies, for example to attend an event or conference or in the form of a research grant. These payments are declared at the start of every board meeting. The Society may receive funding for staff to attend relevant conferences and events, both in the UK and beyond, where it can be shown that The Society and its members will derive demonstrable benefit from the knowledge gained.

Further criticisms made of The Society

191. W1210 also raises concerns in respect of a potential conflict of interest between The Society representing itself as an organisation and trying to act in the best interest of its

members. As stated above, The Society *__is__* its members, therefore it is difficult to separate them both. Without its members The Society would not exist. W1210 also refers to the employment of Debra Morgan as The Society's public inquiry lead given her background. As with all employees of The Society, Debra was appointed as a result of a full and open application process. **GRO-A** was on the interview panel when Debra interviewed for the role. I have been informed that Debra was by far the strongest candidate for the role and, as such, accepted the position.

192. There is a criticism made by W1210 that The Society destroyed documents in the early to mid-1990's *"to draw a line under the HIV issue and move on"*. David Watters was asked to address this in this witness statement and at paragraph 227 he confirms that he is convinced that no documents were destroyed during his tenure. David Watters does recall receiving a telephone call after his departure during which he was informed that documents were being destroyed, but he could not say whether these documents related to matters relevant to the Inquiry's Terms of Reference. This is an allegation that is often made of The Society, however, as far as I am aware nobody has been able to confirm the nature of the documents that are believed to have been destroyed and nobody has stated that they have any recollection of documents being destroyed. The Society has provided approximately 30,000 potentially relevant documents to the Inquiry, and has waived privilege over historic documents that may be of relevance to the Inquiry's Terms of Reference. The Society maintains its position that this Inquiry should not be hindered in its work and that now is the time for all information to be made public.

193. W3261 notes that his late brother *"wrote a letter to the Haemophilia Society around the time he knew he was infected requesting support. I believe the request went largely unnoticed..."* The Society have tried to locate the letter on their database and requested it from the Inquiry but have been unable to obtain a copy. It is therefore difficult for The Society to fully understand and respond to this criticism. However, The Society extends its apologies to W3261 that his late brother felt unnoticed by The Society at the time.

194. W4120 states that in May 1982, after they *"pointed out the dangers of imported blood from a country with an AIDS epidemic"* she was *"viciously attacked" by "some within the Haemophilia Society leadership"*. Due to the lack of specificity about the identity or nature of leadership the subject of the criticism, it is difficult for The Society to respond to this criticism.

Concluding remarks

195. As the CEO of The Society today, I am deeply saddened that people feel that in the past, The Society knowingly and deliberately failed to take action that would have benefitted infected and affected people with haemophilia. As I say, from 1982 onwards, some of those running or overseeing The Society have themselves been infected or affected. The Society is and has always been its members.

196. Since 1991, The Society has run an annual Service of Thanksgiving and Remembrance for those who have died as a result of infected blood products. This has always been an inclusive event with people from all campaign groups attending. [See page 3, (Exhibit HSOC0019923_038)].

197. The Society will say more in its final submissions. But I would like to say, in this statement, that I and The Society of today, with the full support of the Board, have taken on board the contents of the statements to which I am responding. Although I cannot agree with the detail of some of the criticisms of past actions, I recognise that there is hurt and an enduring feeling by some that The Society let them down. I would like those individuals, and all reading this statement, to know that The Society is assisting the Inquiry in every way it can. It wishes to face its past so that it can do better in the future. The Inquiry provides an opportunity for healing. I hope those who have made the statements will feel able to be in contact with me – even if they do not want to identify themselves – so that I can say personally how sorry I am that they feel The Society was not there for them when it was needed.

Statement of Truth

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

Signed **GRO-C**

Dated: 25 August 2022