Witness Name: KATHERINE VICTORIA BURT
Statement No.: First WITN6392001
Exhibits: WITN6392002 to WITN6392267
Dated: 9th April 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KATHERINE VICTORIA BURT

I provide this statement on behalf of the Haemophilia Society ("The Society") in response to the request under Rule 9 of the Inquiry Rules 2006 dated 17 January 2022.

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

Section 1: Introduction

1. I have mainly relied on documents over the period from 1964 to 2021 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 Inquiry's questions, based on my own knowledge, the knowledge of some existing Society trustees and the available documents. This statement responds to the Inquiry's specific questions and also highlights the various campaigns, activities and actions undertaken by The Society in relation to the Inquiry's terms of reference. It 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. However, I hope that it assists in providing a portrait of The Society's activities over the period of time.

Question 1: Please set out your name, address, date of birth and professional qualifications.

2. My name is Katherine Victoria Burt, and I am known as Kate. I am the current Chief Executive of The Haemophilia Society whose registered address is 52B Borough High

Street, London, SE1 1XN. My date of birth is GRO-C 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.

3. I hold a BA Hons and MA Cantab.

4. 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.

Question 2: Please set out your current role at The Haemophilia Society and your responsibilities in that role.

5. As CEO of The Society, reporting to the Board of Trustees, I am responsible for setting the strategic direction of the organisation, ensuring we have high 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.

6. I have attended many of the Inquiry hearings in person or 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.

Question 3: Please outline the purpose and functions of The Haemophilia Society, both currently and historically.

7. 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. As at 31 March 2022, our membership numbers were 4,717 members. The membership has fluctuated over the years but I understand it has remained at around this level for many years. Bleeding disorders are rare and some people are undiagnosed. A current estimate is that there are around 36,000 men, women and children with a bleeding disorder in the UK. Our vision is for anyone affected by a genetic bleeding disorder to have the opportunity 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

8. 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;
   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.

9. We offer free member events, a local group network and online communities to share advice and experiences, as well as the latest news and access to specialist resources. Many people with a bleeding disorder are undiagnosed, or are diagnosed late, because of a lack of understanding about these rare conditions and the community rallies around new members, particularly those newly diagnosed and their families. The Society also campaigns and advocates for what matters to our community; it lobbies government, the NHS and clinicians to demand excellent care and safe and effective treatment, universally available to everyone affected by a genetic bleeding disorder. We are the only UK wide organisation who work across all the devolved nations, requiring an understanding of the variety and complexities of each jurisdiction. We endeavour to work with other groups, where possible, to effect positive change within all the devolved nations for the bleeding disorders community.

10. The Society's objectives and activities are set out in The Society's annual reports. The Society's 2021 Annual Report (Exhibit WITN6392002) states:

> ***Objectives and activities***
>
> *Specific objectives and activities providing public benefit includes:*
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> *Providing information, services and support on all aspects of bleeding disorders, enabling people to live a fulfilled life and be empowered to make informed decisions about their own treatment and care. Information is provided at service events, by phone, email and through a website, active social media pages, publications on specific aspects of bleeding disorders and a network of local groups providing peer support throughout the UK. Running day and residential events and services for members led by expert health professionals and member volunteers in order to provide social support and information.*
>
> *Ensuring that the patients' viewpoint is heard in key NHS and Department of Health forums, for example on the Clinical Reference Group for Haemophilia, and supporting the work of the APPG on Haemophilia and Contaminated Blood*

as Secretariat. Escalating issues of inequalities in care and concerns over access to care to the NHS and government health teams.

Advocating for fair treatment and support for those impacted by the contamination of blood products supplied by the NHS in the 1970s and 1980s and cooperating with the public inquiry into infected blood.

11. At present, support for our member community is available online, face-to-face and over the phone. The charity's supporters help fundraise the costs that are vitally needed to be able to offer membership – and services such as events and printed publications – entirely free to all members. We offer:

    a. support through local groups across the UK, free membership events for people at all stages of life, and a vibrant online community, where people affected by bleeding disorders can find friendship, a listening ear, information, and share their views and experiences.
    b. Regular email updates and mailings on the issues affecting people with bleeding disorders: services, opportunities, campaigns and the changing NHS.
    c. Publications to help members understand more about life with a bleeding disorder.
    d. Expert, in-depth resources and news updates keep members informed and help equip them with knowledge and confidence. This includes practical information on practical matters (like where to find help with benefits); and a twice yearly members' magazine, Community Matters, which includes new insights, inspiring stories and experiences.
    e. The opportunity to vote at The Society's Annual General Meeting and elect Trustees – or to become a Trustee.

12. Our peer support – through local groups around the UK and our online community – offers friendship and a listening ear when needed, as well as enabling people to share their views and experiences. By bringing people together for information and support at events tailored to all life stages, we amplify their voices to reduce isolation and influence government, welfare and health care policy. Our community is at the heart of everything we do – we collaborate with members and health professionals to ensure we make decisions influenced by their valued input and direction.

13. As bleeding disorders are rare, many people will never encounter The Society; we are largely invisible beyond the communities we serve. So, we must work doubly hard to raise both awareness and understanding of bleeding disorders and the vital funds needed to give those affected the services they deserve and need to live the best life they can.

14. Together with its members, The Society has also campaigned on behalf of people affected by bleeding disorders for over 70 years, continuously lobbying government, the NHS and clinicians for the best possible care, safe and effective treatment, and equitable access for all. Haemophilia Societies around the world have been politicised by contaminated blood. Small organisations have had to fight huge political battles. Without the impact of contaminated blood, The Society would have been able to utilise more of its resources for campaigning for better treatment and care for its members. Instead, it has had to spend years lobbying various governments for support schemes, access to safe products, an inquiry and compensation.

15. The activities that are currently offered through membership include:

    a. Annual members conference: This is an annual event offering a range of informative, interesting and empowering sessions. By way of example, in 2021, sessions included Trauma, Mental Health and Living with a Bleeding Disorder; Evolution of treatment for haemophilia; Advocating for Change; Von Willebrand Disease, Update on new guidelines; Mild or moderate bleeding disorder – How will it affect my life?; Physiotherapy best practice – What patients should expect from their haemophilia Centre; 10 European principles of care for women and girls with inherited bleeding disorders.
    b. Newly Diagnosed Family Weekends: Newly Diagnosed Weekends give practical and emotional support for the whole family, including dedicated time and space to meet and learn from medical experts and each other. These events are aimed at parents who have recently found out their child has a bleeding disorder and bring together experts in bleeding disorders so that families get the help they need to ensure their child receives the best possible care.
    c. Webinars: As a reaction to changing circumstances of the Covid-19 pandemic, we introduced a series of virtual meetings covering a range of topics under the heading of *Bleeding Matters Live!* These sessions included updates about the peer review report on the audit of centres; sharing

experiences on changing treatments and virtual consultations; back to school; and mindfulness training.

d. Youth Camp: Our young members can struggle to cope with having a bleeding disorder and having to get treated every few days. This sometimes has restrictions on activities they can do and therefore miss out on having fun. Our summer camp held in July or August for five days allows children to understand more about their bleeding disorder and raise their confidence levels. It also gives them the chance to understand how teamwork and determination can benefit them.

e. Youth Ambassadors: In 2015, The Society launched an exciting new programme to encourage, develop and empower our young members to become our future leaders and advocates and support them in their career development.

f. Ageing support: We aim to reduce isolation and provide information and support for our community as they get older. The majority of our members aged 30+ are living with co-morbidities such as HIV, hepatitis B and hepatitis C, and may also have been told they are at risk from vCJD. Our services offer a safe environment for people to share their experiences with others who have similar diagnoses, providing information, support and the opportunity to meet others. We want to ensure all our services meet the needs of our members and are designed with this community in mind.

g. Family days: Families and individuals affected by a bleeding disorder can often feel a sense of uncertainty and isolation. Our local groups provide a vital network of mutual support for people with bleeding disorders around the United Kingdom enabling members to meet others in their local community. Family days are run by our local groups as a support network, creating invaluable friendships between families. We are currently developing a care home resource pack that will be available for members which provides information for care home staff.

h. Women's awareness and Talking Red Programme: Tens of thousands of women across the UK are living with symptoms of a bleeding disorder without even knowing it. Talking Red is The Haemophilia Society's campaign that urges everyone to talk about women's bleeding. It helps women become more aware of the symptoms of a bleeding disorder – heavy periods, bruising easily and prolonged bleeding after a procedure or childbirth. Our women's awareness events aim to promote better understanding of what it means to live with such a condition. We want to empower women, share knowledge and spread the word that help and support is out there. Women's bleeding disorders can have a big impact mentally, physically and financially. Yet many people still don't know that women can be affected by bleeding disorders.

i. Day to day: We publish resources online to help direct people to the right resources, whether they are someone with a bleeding disorder, a parent or carer. Topics include: healthy living travel; benefits; career choices; pain management; positive mental health; friends, family and carers support; bleedings disorders and school; and insurance.

j. Service of Thanksgiving and Remembrance: This is an annual service for all those people with inherited bleeding disorders who have died due to their treatment with contaminated blood products. We welcome all who have been affected by this tragedy to this annual service.

16. In the balance of this section, I refer to documents and evidence given to the Inquiry about the historical objectives of The Society. Information about the purpose and function of The Society can be found at the beginning of each of The Society's annual reports. The Society's Annual Report for the year ended 31 December 1966 (Exhibit WITN6392003) 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."*

17. 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 WITN6392004). 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.*

18. 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."*

19. The Society's Annual Report from 1985 (Exhibit WITN6392005) 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.*

20. 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."*

21. 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."*

22. Minutes of an Executive Committee meeting on 5 October 1991 (Exhibit WITN6392006) 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.*

23. 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 explains 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 and The Society played a crucial role in addressing some of the resulting problems. He says 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.

24. Simon Taylor further explained 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.

[23] Reliable information was difficult to obtain, both because it was a new and emerging threat about which little was known, but also in the early days there had been differences in opinion by clinicians as to the impact on people with haemophilia.

[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.*

25. Simon also set out some of the other work undertaken by The Society, for example, lobbying 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 about the requirement for The Society to also deal with the media. Not just responding to media queries, but also allaying members' concerns about what the media was reporting. Simon Taylor also stated, "*As the second emerging impact of HCV became clearer over time, all of the above activities also applied and multiplied*".

26. 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 WITN6392007). 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 organisation.*

27. 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, perhaps evidences the importance she attached to lobbying and campaigning.

28. 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 in the six years 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".* 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".*

29. 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.

Question 4: Please outline the current structure of the Haemophilia Society, in relation to:

- **a. how, and by whom, key strategic decisions are made;**
- **b. how it is funded; and**
- **c. the structure and functions of its various committees or working groups,**

and please explain how the structure of the Haemophilia Society has changed over time in these respects.

4(a) How and by whom, key strategic decisions are made

30. The Society is a registered charity in England (number 288260) and Scotland (number SCO39732) and company limited by guarantee (number 01763614). The Society's governing document is its Memorandum and Articles of Association. The most recent version (as amended on 17 September 2020) is exhibited to this statement (Exhibit WITN6392008).

31. The Society's key strategic decisions are primarily made by The Society's Board of Trustees, which delegate operational responsibility to me as Chief Executive. The staff team report to me: member services, events, fundraising, finance and HR.

32. The Society's board of trustees meets five times each year to give strategic direction to our work. Trustees are responsible for governing our organisation, and as a smaller charity, they make a real difference to what we do.

33. Trustees are volunteers who draw on personal experience of living with a bleeding disorder, or wider knowledge and expertise in for example, charity governance, fundraising, finance, communication, advocacy, understanding of the NHS or government relations.

34. The Society's Board of Trustees has seven ordinary Trustees (elected by members of The Society); one Honorary Chairman; two honorary Vice-Chairmen; and up to four co-opted Trustees. Co-opted Trustees may be appointed as the charity's Honorary Treasurer; and the Trustee Board may also appoint one or more Honorary Medical Advisers to the Charity. Elections take place prior to the Annual General Meeting in November each year and Trustees are elected for a three-year term. They may stand again for election for a further three-year term and then must take at least one years' break. One further three-year term as a Trustee is permitted but having served nine years, an individual may not stand for election or be co-opted to the board again.

35. A call for nominations is sent to all of The Society's members in September each year requesting Trustees' nominations signed by another member. The Chair is appointed to the Board following an interview process.

36. The Board of Trustees are also members of five sub-committees, which are the Finance & Risk Committee, the Nominations Committee, the Governance Committee, the Public Inquiry Committee and the Women's Committee.

37. The Society also has a number of people who hold important honorary roles (such as President and Vice President), but who are not involved in day-to-day strategic decision-making.

38. Specific details about The Society's current and former Presidents, Vice Presidents, Chief Executives and Board of Trustees are included in our 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 this statement at Exhibits WITN6392009 to WITN6392058 and WITN6392143.

39. For the remainder of this section, I draw to the Inquiry's attention the evidence of former staff and Trustees of The Society who provide information about how and by whom, key strategic decisions were made before I joined The Society.

40. David Watters (who was employed by The Society between 1981 and 1994) comments at paragraphs 11 to 12 of his statement dated 18 January 2021 [WITN3429001]:

> *[11] When I joined, there was a Board of Trustees and the Executive Committee. The Board of Trustees and Executive Committee were exactly the same body, there was no difference between them. The Executive Committee was the supreme decision making body of The Society. The Council sat below the Executive Committee. The Council consisted of two representatives from each local group. There is a simple illustration of the structure of The Society as at 1981 in [WITN3429002/PRSE0003316]. In the same document, there are 28 local groups listed on page 16. By 1988 there were 30 local groups referred to in the Annual Report [WITN3429003/HCD00000276_021]. Information flowed to and from the membership and information flowed to and from local groups of The Society.*
>
> *[12] The Council would meet with the Executive Board two or three times a year. Whilst the local groups were often in correspondence with each other they rarely met outside the meetings with the Executive, as far as I am aware. There*

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

41. 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]:

> *[10]… The governing body of the charity was and is the Trustee Board, which holds responsibility for strategic decisions about priorities and use of resources.*
> *…*
> *[16] The Society was a national charity, with an elected board. The legal governance of the charity was then, as it is now, a Trustee Board, which delegated operational responsibility to a CEO. I believe the Inquiry will be able to confirm this by reference to the Articles and to statutory report and accounts 1998 to 2004, which I do not have, and minutes for the members over this time period. The staff team reported to me as CEO, and the membership. Within the staff team, each had specific roles and job descriptions within: membership services; finance; administration; and fundraising. Specialist staff roles included a Hepatitis C and an HIV officer, as well as a children and families officer, and a benefits advisor.*
>
> *[17] The trustee board met regularly, at least every two months; extraordinary meetings were sometimes held where specific urgent issues needed to be resolved. Within the Trustee Board, there were a number of Honorary Officer roles: Chairman, Treasurer and two Vice Chairmen. The charity also had an honorary President (Lord Alf Morris from 1999) and a number of Vice Presidents. The membership elected the Board and the Chairman, and trustees were then appointed the Honorary Officers from within their group. There was a Royal Patron: HRH The Duchess of Kent. When I first joined, the Chairman was Chris Hodgson who was later succeeded by Roddy Morrison who took office following the AGM on Saturday 5 July 2003.*

42. Simon Taylor, Executive Committee Member/Trustee of The Society from 1998 to 2002, says in his statement dated 22 April 2021 [WITN4500001]:

> *[32] At all times I was a Trustee, I acted on a voluntary non-executive basis, with all day- to-day decisions being made by the Society staff, usually in consultation with the Chairman. The Executive Committee normally met every one or two months to discuss and decide major matters and set direction for the staff. Task groups and sub committees would meet between Executive meetings as required by the Chair of the group and relevant staff.*

43. Medora Ann Hithersay, a Society Trustee from January 2004 to December 2010, says in her statement dated 2 February 2021 [WITN3206003]:

> *[3] I joined THS as a Trustee in January 2004 and I retired in that role in December 2010, however I had relationships with THS prior to that as part of my role as Chief Executive at the Macfarlane Trust, from as early as 1997.*
>
> *[4] My role entailed attending Trustee Board meetings, discussing the various matters that appeared on the agenda, going to conferences, going to the AGM, visiting local haemophilia societies around the country, including in Ireland and the associate organisation in Scotland. The role also entailed supporting our Fundraiser and his team, and discussing matters connected with the use of funds for THS, and the need for additional funds from time to time for specific projects.*

44. My personal view from what I have learned from the evidence I have seen and gathered from talking to colleagues, is that key strategic decision making at The Society is not easy. People with a bleeding disorder have that disorder in common, but it does not define them nor is it a reliable indicator of their stance on key issues. People with haemophilia are individuals, just as much as people who do not have a bleeding disorder, and there is a wide diversity of thought within the community. Some individuals have very formed opinions and are happy to voice them but these may not necessarily represent the memberships' views. Others have strong views but do not make them known to the trustees. Parent members may be concerned only with matters relevant to children. Some of those not affected by infected blood do not necessarily understand the relevance of understanding the failings of the 70s, 80s and 90s to their situation now.

45. It is clear from the evidence (see for example letters to the editor and the editorial by David Evans in the fourth edition of The Bulletin 1998 (Exhibit WITN6392059) that the plurality of viewpoints within one membership poses a challenge when it comes to key strategic decision making. Decisions have to be made and it falls to the trustees to make them.

46. On a wider level, The Society makes a point of holding its core events around the UK to engage with as many members as possible. Since Covid-19, we've hosted events in York, Manchester, Essex, Surrey, Derbyshire and London, with events due to take place later this year in Oxford, Belfast and Glasgow. A key priority under my leadership is to strengthen our local groups in England, Scotland, Northern Ireland and Wales in order to better understand individual experiences of access to treatment as well as to foster a more effective community support network

4(b) How is The Society funded?

47. The Society receives money from community fundraising by members and volunteers; grant and trust income; corporate income; and legacy income. This funding helps support projects such as the Newly Diagnosed Weekends, Talking Red, and Youth Ambassador projects. Like many charities working in the healthcare sector, including haemophilia societies across the UK, Europe and around the globe, the EHC and the WFH, a proportion of that funding comes from pharmaceutical companies. Some of our work may also be funded indirectly by pharmaceutical companies, particularly in connection with projects linked to the EHC and the WFH. Information about pharmaceutical companies that support The Society is published on our website; and we always acknowledge when companies have sponsored The Society's events. We endeavour to have at least two sponsors for any event from different companies. This is addressed in further detail in the section about The Society's relationship with pharmaceutical companies in section 4 below.

48. I have recently reflected on an article published in the New England Journal of Medicine titled "Conflicts of Interest for Patient-Advocacy Organizations" by Matthew McCoy, Michael Carniol, Katherine Chockley, John Urwin, Ezekiel Emanuel, and Harald Schmidt dated 2 March 2017. I reflected on this article, which talks about patient-advocacy organisations managing conflict of interest in light of our relationship with pharmaceutical companies. This article poses three questions to organisations like ours: First, to what extent do patient advocacy organisations disclose information

necessary for assessing possible financial and other conflicts of interest?; Second, how frequently do patient-advocacy organisations have financial and other conflicts of interest?; and Third, do patient-advocacy organizations have policies to minimize and manage conflicts of interest? From The Society's perspective, in relation to the first question: The Society publishes its full accounts and any funding from pharmaceutical companies is always disclosed. For example, when pharmaceutical companies support events or programmes, we are fully transparent about this and publish it on our website. In relation to the second question, we start off all our board meetings by making any disclosures about work trustees have been doing with pharmaceutical companies. In relation to question 3, The Society's board meetings typically start with disclosures being made. Any trustee who may have a conflict of interest is asked not to take part in a discussion or vote on any issue where there may be a perceived conflict of interest.

49. The Society is also funded using money from legacies and community fundraising. A breakdown of how we are funded can be found in our Annual Reports, which are published every year. The Inquiry has been provided with all of the Annual Reports currently available to The Society.

50. Historically, The Society's fundraising was mainly grassroots and led through local groups. Documents I have seen show that The Society has a history of being transparent about its funding sources. For example, The Society's 1970 Annual Report (Exhibit WITN6392015) includes at page 7 a list of Trusts, firms and organisations who contributed to The Society's funds during 1970. The same list is reproduced at page 2 of The Society's Financial and Appeals Sub-Committee Report for 1970 (Exhibit WITN6392060).

51. The Society's Annual Report from 1986 (Exhibit WITN6392030) sets out a list of donors throughout the year. There are separate lists for 'Corporate donors'; 'Grant Making Trusts, School, Churches, Clubs etc'; and 'Individuals who gave £50 or more'. The Society's 1989 Annual report (Exhibit WITN6392033) sets out similar lists; and I draw the Inquiry's attention to the extent of different companies that contributed donations, listed at page 12 under the heading 'Trusts and Companies'.

52. An example of external fundraising by The Society can be seen in Minutes of the Executive Committee of The Haemophilia Society meeting, 4-5 October 1991 at page 7 (Exhibit WITN6392061):

> *ii) Fundraising: Mr Watters reported that McDonald and Associates were helping to build funds and lay down sound financial foundations for the future. They had raised some £40,000 since coming to the Society. Mr Douglas Jack was Mr Watters' man in the office and he liaised with Mr McDonald. The End to End Bike Ride had been the Society's first national fundraising event and it was hoped it would be repeated. Indeed, similar national events would have to be repeated if more money, as well as the Society's public profile, were to be raised.*
>
> *The Fundraising Committee, chaired by Mr David Miller, would be meeting twice a year. It would be operating at a higher, corporate donor, level and Mr McDonald would be one of its advisors. Mr Taylor observed that it was difficult to get across to potential donors what the Society aims were, why the money was needed and what the Society could offer. A discussion followed during which* GRO-A *said that the issues that needed to be addressed were whether or not the needs of people with haemophilia were being served; targets needed to be set, followed by the raising of the funds to meet those targets.*

53. Minutes of an Executive Committee meeting on 7 May 1994 (Exhibit WITN6392062) record that there was a fundraising presentation by John Berry, during which a fundraising strategy was presented. The key elements of the strategy were Core Funding from Statutory Sources; Trusts and Companies; Members and Individuals; Legacies and Fundraising Events such as the Annual Draw.

54. In the past, the range and quality of the publications and events that The Society produced and provided was out of proportion to its modest income stream: it did a great deal with not a lot. We aspire to continue to punch above our weight in this regard. Currently, The Society receives no government funding and has received none since 2013/2014. For further details of government funding in the past, please refer to the response to question 26 below.

55. Below are The Society's major projects for 2019/2020 with details of their main funding sources. I have provided a list for the year 2019/2020 because this gives the most accurate picture of the services that we typically provide to our members. The Covid-19 pandemic limited the range of services that we provided in 2020/2021 and 2021/2022; and we have not yet completed planning for our work in 2022/2023.

a. Talking Red, funded by Takeda
b. Newly Diagnosed Family Weekends funded by Spark, Roche/Chugai, BioMarin
c. Youth Ambassadors and Youth Activities, funded by Sobi
d. Online events funded by Sobi, Takeda, Novo Nordisk, Spark, BioMarin
e. Advocacy work funded by CSL Behring, Sobi, Roche/Chugai
f. Member Conference funded by Roche/Chugai, BioMarin, Novo Nordisk, Sobi
g. Publications funded by Sobi, Roche/Chugai, Takeda, BioMarin, Spark

56. As per guidelines of the Association of the British Pharmaceutical Industry ("ABPI"), all of these donations with pharmaceutical companies are contracted with specific clauses underlining that the sponsoring companies do not have any control over the content or format of the activities provided. These are publicised on our website and as per ABPI guidelines the sponsored activities acknowledge the funding provided for full transparency.

57. On rare occasions, information may be developed with a company in a partnership agreement, again this is contracted, and the input of the company acknowledged in any of the materials produced.

58. We sometimes distribute information and literature developed by pharmaceutical companies that has been specifically designed for the bleeding disorder community, we will review and if thought to be of benefit to our membership we will disseminate. This can include books and games for children and online information and applications.

59. Specific details about The Society's funding are set out in each of The Society's Annual Reports. Each year, there is also an independent auditor's report prepared to the members of The Society, which is also included in The Society's Annual Reports.

60. The Society's resource in relation to its work on the Infected Blood Inquiry (excluding legal fees) has been funded from a legacy that was left to us for work on contaminated blood. No money from pharmaceutical companies has been received or used for this work.

61. Our investments are managed through the CCLA (Churches, Charities and Local Authorities) Investment Management Limited. The fund is approved by the Charity

Commission as a Common Investment Fund and provides a client-driven ethical investment policy.

4(c) The current structure and functions of The Society's various committees or working groups

62. As stated above, The Society currently has five Sub-Committees, which are the Finance & Risk Committee, the Nominations Committee, the Governance Committee the Public Inquiry Committee and the Women's Committee.

Finance & Risk Committee

63. The purpose of the Finance & Risk (F&R) Committee, as stated in the Terms of Reference for the F&R Committee (Exhibit WITN6392063) is set out below:

> *F&R will assist the Board by providing analysis, advice and oversight of the organisation's ongoing finances and risk register.*
>
> *Lack of oversight of the organisation's finances could lead to insufficient funding to deliver services to members and the wider bleeding disorder community.*
>
> *The absence of regular monitoring of income, expenditure and risk could lead to a failure to attract grants and donations and loss of trust in THS causing significant budgetary underperformance and ultimately an inability to deliver services and significant risk to the future of THS.*
>
> *The Group aims to help the Board:*
>
> - *Provide financially based support and recommendations to the Board*
> - *Review and recommend financial policies and procedures.*
> - *Support and review The Risk Register.*
> - *Review quarterly financial results compared to budgets.*
>
> *It is important that the trustees as a Board retain overall responsibility for all finance and risk related areas. Part of the role of F&R will be to assist the Board to seek external professional advice where appropriate. However, it is*

> *advisable to include members with finance and risk experience and/or qualifications where possible.*

Nominations Committee

64. The purpose of the Nominations Committee is stated in clause 74(7) of The Society's Memorandum and Articles of Association (Exhibit WITN6392008) as follows:

> *the Trustee Board shall establish a Nominations Committee which shall (i) meet with members who have been nominated to stand for a Trustee position on the Trustee Board to inform them of the requirements for the role; (ii) interview persons who are under consideration by the Trustee Board as potential Co-opted Trustees or Honorary Chairman; and (iii) recruit an Honorary Chairman (including, where appropriate, advertising externally for suitable candidates) and making the appropriate recommendation to the Trustee Board;*

Governance Committee

65. Establishing the Governance Committee will assist the Board to take all appropriate actions to ensure compliance and good governance and would be in the charity's best interests. Poor governance and non-compliance could risk The Society's ability to continue its activities while compliance and good governance helps ensure best practice and quality of services. It is essential that the Board addresses compliance and governance. The Board felt that creating the Governance Committee was an effective way of minimising these risks and ensuring an ongoing focus on compliance, governance and related issues.

66. The Governance Committee aims to help the Board:
    a. Identify and address compliance and governance related issues and risks.
    b. Progress actions in relation to these.
    c. Prepare documentation required or desired to ensure compliance and good governance, limit and mitigate risk and promote best practice and procedure.
    d. Manage priorities and Board time in relation to these areas.

67. It is important that the trustees as a Board retain overall responsibility for all compliance and governance related areas. Group members will not necessarily have any expertise or experience in relation to any of the issues they are considering, they

will not hold themselves out to have any, or be acting in any professional capacity. Their views and work should not be relied on as correct. Part of their role will be to assist the Board to seek external professional advice where appropriate.

Public Inquiry Committee

68. The Public Inquiry Sub-Committee was set up to follow the process of the Infected Blood Inquiry and report back to the full board. This sub-committee was set up with people who are infected and affected by infected blood and part of their remit is to offer advice and guidance as to the actions of The Society in connection with the Infected Blood Inquiry. Retired trustees who have been affected by infected blood have been extended membership of this subcommittee, whilst maintaining quorum, to ensure consistency and a strong voice from those directly affected steering the actions of The Society.

Women's Committee

69. The Women's sub-committee Regulations (Exhibit WITN6392064) set out the aims of the sub-committee's work as follows:

- *To raise awareness of girls and women with bleeding disorders and the issues that affect them to enable them to find support and identity.*
- *To reach out to and educate girls and young women about periods and support through school years.*
- *To inform and support girls and women with bleeding disorders to access diagnosis and treatment options.*
- *To educate women about pregnancy and child birth with a bleeding disorder.*
- *To campaign for sanitary protection to be free to women with bleeding disorders.*

Historical structure and functions of The Society's various committees or working groups

70. In the remainder of this section, I draw to the Inquiry's attention the evidence of former Trustees and staff members of The Society who provide information about the structure and functions of The Society's various committees or working groups.

71. In his statement dated 18 February 2021 [WITN3429001], David Watters sets out the different committees and advisory bodies that were set up within The Society during his time at The Society, as far as he can recall. Mr Watters describes the purpose, functions and responsibilities of each committee or advisory body, including the Blood Products Committee, the Case Committee, the Research Grants Committee and the Medical Advisory Panel. He states as follows:

> *29. At all stages there was a Medical Advisory Panel, and I believe the Blood Products Committee, and the Case Committee. I am aware that I informed the Penrose Inquiry that I did not think that the Blood Products Sub-Committee existed when I joined The Society, however, I now believe that it did. There were also other sub-committees as the needs arose. For example, if fund raising was in difficulty we would set up a fund raising sub-committee, there is also reference to a Case Committee and a Research Grants Committee in February 1984 [WITN3429007/HSOC0029476_033] and Policy Committee in Executive Committee minutes dated 14 November 1991 [WITN3429008/HSOC0010385]. In essence, the committees were often established so that there was somebody else to share ideas with me because at the end of the day I was responsible for fund raising, staff welfare, recruitment of staff, management of the office, equipment, the building, as well as everything else. I would more often than not attend those sub-committee meetings, however, it was mainly to minute the meetings.*
>
> *[30] The Blood Products Committee. The purpose of this committee was to keep under review and, in particular, to be constantly on the back of the Department of Health about the achievement of self-sufficiency in the United Kingdom. Had we been self-sufficient in the late 70s, I have no doubt, that the outcome would have been very, very different. I do not mean that we would not have been in a situation where we had no Hepatitis and no HIV, but it would be much, much less and that's where successive governments, and successive Ministers of Health really failed us down the line.*
>
> *[31] The Case Committee. The purpose of this committee was to consider the giving of grants to families in need. I have no recall of members, however, I do recall that the Committee would consider applications and then place anonymous proposals before the Executive Committee for consideration.*

> *[32] The Medical Advisory Panel. This was a panel of leading clinicians in the field whom The Society could turn to whenever necessary to request their opinion and advice in relation to developments in the treatment of haemophilia.*
>
> *[33] I have been asked to comment on the Treatment and Care Committee and the General Services Committee. Unfortunately, I cannot recall the detail of either of these committees, however, I would assume that the Treatment and Care Committee dealt with the standards of treatment and care across the country, because certainly in the early days they were not consistent. I have no recollection at all of the General Services Committee.*

72. Reports about the work of the Treatment and Care Working Group are recorded in minutes of The Society's meetings. An example of the scope of the work undertaken by this working group can be found in the minutes of the meeting of the Council of The Society on 14 March 1987 at pages 2 to 3 (Exhibit WITN6392065):

> *(c) Treatment and Care: Mr Milne also reported on this Working Group mentioning, in particular, new Welfare Benefits Notes which were being prepared by Mr Pegram. The Working Group had rejected using anyone other than the General Secretary to represent people with haemophilia at Tribunals, etc, in view of the degree of knowledge of haemophilia required. The Working Party was also planning a survey of employment status in people with haemophilia. Representation had also been made to the sub-committee of the Haemophilia Centre Directors' Organisation dealing with the re-organisation of haemophilia care in the UK.*
>
> *The General Secretary also amplified the possible benefit of the outcome of a Court of Appeal ruling on Attendance Allowance (the case of Moran), announced the previous day. It was noted that the finding of the Court of Appeal could be subject to appeal to the House of Lords by the Department of Health and Social Security-*
>
> *Questions were also raised concerning confidentiality of HIV test results and the reactions of some doctors (GPs) and dentists to patients with positive antibody test results. It was STRESSED that all instances of questionable practice by health care professionals should be reported directly.*

73. Minutes of a Meeting of the Council of The Society held on Saturday 17 September 1988 (Exhibit WITN6392066) record the following report in relation to the Blood Products/Treatment and Care working group:

> *(b) Blood Products/Treatment and Care: [REDACTED] (South Essex) urged Groups to place greater emphasis on the supply and the availability of treatment since this was, perhaps, the most important aspect of the Society's work. Ken Milne also reported additionally on the monoclonal product, reporting the reservations held by members of the Medical Advisory Panel expressed at the recent meeting with them.*

74. Simon Taylor (who was an Executive Committee Member/Trustee of The Society from 1998 to 2002) gave evidence in his statement dated 22 April 2021 about various committees he could recall, including the Policy Committee, Services Committee, Finance Committee, Publications and External Relations Committee, Blood Products Task Group, Hepatitis Campaign Group, Hepatitis Task Group and International Task Group. He states [WITN4500001]:

> *[37] It was the working practice of the Society to regularly set up sub committees and task groups as needed. Some of these were short term, others were semi-permanent; the names changed sometimes, whilst the function might remain unchanged. All members of the Executive were allocated to a range of committees based on a combination of personal interest and direction by the Chair of the Society depending on skills and experience.*
>
> *[38] I cannot recall details of all the groups that existed, or the period that I was a member of any specific group over the 14 years I served on the Executive Committee.*
>
> *[39] The detailed remit of these groups would change over time, and the Inquiry can ascertain details from Society minutes of meetings.*
>
> *[40] I do not recall specific details of if, or when, I was a member of any of these groups , however my broad recollection is that in general terms the remits were fairly straightforward:*
>
> - *Policy Committee looked at topics such as blood product safety etc;*

> *• Services Committee was responsible for services to members including publications, information days, support with benefits etc;*
>
> *• Finance Committee — Finance and administrative matters and fund raising;*
>
> *• Publications and External Relations — Oversee publications including 'the Bulletin' — at times the Committee also looked at communication with government and politicians if not covered by another committee;*
>
> *• Blood products task group — to review issues relating to blood products, particularly safety and supply. [HSOC0003722] refers.*
>
> *• Hepatitis Campaign Group — in conjunction with the staff and our professional advisors (PR and Lobbying) to oversee the campaign for support for people impacted by HCV infection. Minutes of the Hepatitis Task Group 11 Jan 1995 para 3 gives an account of the work of the group. [HSOC0003794]*
>
> *• Hepatitis Task Group — in conjunction with the staff, and the Manor House Group to gather information on the impact of HCV and advise the Executive Committee on actions.*
>
> *• International Task Group — remit included relations and working with the World Federation of Haemophilia, the European Haemophilia Consortium (EHC), and twinning with other national haemophilia societies. [HSOC0003722] refers.*
>
> *…*
>
> *[41] Full details of Committee 'A' and Committee B' are set out in the Minutes of the Executive Committee meeting dated 1 July 1993 [HSOC0024828] including membership. I was a member of the committee along with other trustees. The committee was Chaired by the late Mr Ken Milne. My recollection was that de facto, Committee 'B' was the Policy and Services Committee by another name. As such I believe the Committee looked at topics such as blood product safety as well as services to members including publications, information days, support with benefits etc.*

75. 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]:

> *[25] As referenced above in my responses to questions 5 and 6, the legal governance structure of the charity, consisted of the Trustee Board, which appoints the CEO, to whom day to day management of the organisation is delegated. As CEO, I reported to each Trustee Board meeting on operational matters. The Board also delegated responsibilities in three key areas to formal*

> *Sub Committees: Health, Resources and Information and Communications. Each was chaired by a Trustee Board member, and I was a member of all three as CEO. The Society holds in its archives copies of the minutes for all Board and Sub Committee meetings held during my tenure, and I have been able to review copies provided in preparing my evidence. The minutes provide a detailed record of strategic and operational matters discussed, and of decisions taken.*
>
> *[26] The Council had no governance role, and had no delegated powers; its role, to my recollection, was to provide a forum for representatives of the Society's local groups and the Trustee Board to meet twice a year. There was no formal relationship that I can recall; the Council was part of the way the Society engaged with its local groups (branches) and functioned mainly as a forum for meeting together, twice a year. The Council did not undertake any programmes of work or activities in its own right. Further information on this can be found in member communications by the Society during my tenure, and in Board minutes.*

76. Karin Pappenheim also gives evidence about various other membership groups that were part of The Society:

> *[19] The structure of the charity included local membership groups of the Society, which provided a focus for membership peer support, fundraising and campaigning. I believe there were approx. 25 groups across the UK during my tenure.*
>
> *[20] The local groups (called branches) operated within a framework established by the Society and a group bank account scheme. This is a specific and recognised charity structure with local branches forming part of the national charity. As branches of the charity, the groups were active in fundraising and providing peer support to members in their own locality. They also took part in campaigns with the Society. The groups were not separate legal entities, they formed part of the membership structure of the Society and hence under charity accounting practice the national charity accounted for the group finances. Each group had to follow the accounting and other rules set by the national charity, which involved submitting regular reports and accounts. Groups held regular meetings, providing peer support for individuals and families, and reported their*

activities to the Society. News and information from the groups was included in the Bulletin (the Society's member magazine) and all groups with contact details were listed in the publication. A board member was assigned to each group to act as a liaison point between the branch and the national charity. These board/group links were appointed by the trustee board from amongst their members each year to the best of my recollection.

[21] A number of special interest groups were also active as part of the organisation during my time with the Society: the Manor House Group for those affected by 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.

77. Minutes of The Society's meetings show that there have been numerous sub-committees and working parties throughout The Society's history. In addition to the committee's already set out above, set out below are a number of the other committees and working parties that I am aware of from the documents that I have been shown:

a. Overseas Sub-committee (as noted in The Society's 1982 Annual Report at page 10 (Exhibit WITN6392026); in The Society's minutes of meetings of the Council of the Haemophilia Society (see for example minutes from a meeting held on 10 March 1984 at page 1 (Exhibit WITN6392067); minutes from a meeting held on 15 September 1984 at page 2 (Exhibit WITN639268); minutes from a meeting held on 24 November 1984 at page 3 (Exhibit WITN6392069); and minutes of meetings of the Executive Committee (see for example minutes from a meeting held on 12 January 1984 at page 3 (Exhibit WITN6392070); minutes from a meeting held on 9 February 1984 at page 4 (Exhibit WITN6392071); and minutes from a meeting held on 8 November 1984 at page 5 (Exhibit WITN6392072);

b. Administration Sub-Committee (as noted in minutes of a meeting of the Executive Committee (see for example minutes from a meeting held on 12 January 1984 at page 1 (Exhibit WITN6392070). This Sub-Committee appears to also have been referred to as the "Computerisation/Administration Sub-Committee" in the minutes from a meeting held on 9 February 1984 at page 1 (Exhibit WITN6392071);

c. Internal Organisation and Resources Sub-Committee (as noted on the Agenda of the Informal Executive Committee Meeting on 1 July 1993 (Exhibit WITN6392073);

d. External Relations and Provision of Services Committee (as noted on the Agenda of the Informal Executive Committee Meeting on 1 July 1993 (Exhibit WITN6392073);

e. Resources Sub-Committee (as noted in minutes of the Minutes of the meeting of the Executive Committee, held on 16 March 1994 (Exhibit WITN6392074 and Minutes of the Trustees meeting on 11 July 1998 (Exhibit WITN6392075);
f. Fundraising Committee (which was a sub-set of the Resources Committee and later renamed to “Friends of the Haemophilia Society”, as noted in the Minutes of the Executive Committee meeting on 1 July 1992 (Exhibit WITN6392076A);
g. Services Sub-Committee (as noted in Minutes of the meeting of the Executive Committee, held on 16 March 1994 (Exhibit WITN6392074);
h. Health sub-committee (as noted in minutes of the Trustees meeting on 11 July 1998 (Exhibit WITN6392075);
i. Information and Communication sub-committee (as noted in minutes of the Trustees meeting on 11 July 1998 (Exhibit WITN6392075);
j. Treatment and Care working party (as noted in The Bulletin 1987 (No. 4) at page 7 (Exhibit WITN6392077); Minutes of Society's Executive Committee meeting on 14 September 1989 (Exhibit WITN6392076); Minutes of the meeting of the Council of The Society on 28 November 1987 (Exhibit WITN6392078); Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); Minutes of the meeting of the Council of The Society on 18 March 1989 (Exhibit WITN6392080); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081); Minutes of the meeting of the Council of The Society on 17 March 1990 (Exhibit WITN6392082); Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083); Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084); Minutes of the Executive Committee of The Society on 16 June 1988 (Exhibit WITN6392085); Minutes of the Executive Committee of The Society on 8 September 1988 (Exhibit WITN6392086); Minutes of the Executive Committee of The Society on 10 November 1988 (Exhibit WITN6392087); and Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).
k. Finance and General Purpose working party (as noted in Minutes of Society's Executive Committee meeting on 14 September 1989 (Exhibit WITN6392076B); Minutes of the meeting of the Council of The Society on 28 November 1987 (Exhibit WITN6392078); Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); Minutes of the meeting of the Council of The Society on 18 March 1989 (Exhibit WITN6392080); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081); Minutes of the meeting of the Council

of The Society on 17 March 1990 (Exhibit WITN6392082); Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083); Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084); Minutes of the Executive Committee of The Society on 8 September 1988 (Exhibit WITN6392086); Minutes of the Executive Committee of The Society on 10 November 1988 (Exhibit WITN6392087); and Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).

l. Publications and External Relations working party (as noted in Minutes of Society's Executive Committee meeting on 14 September 1989 (Exhibit WITN6392076B); Minutes of the meeting of the Council of The Society on 28 November 1987 (Exhibit WITN6392078); Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); Minutes of the meeting of the Council of The Society on 18 March 1989 (Exhibit WITN6392080); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081); Minutes of the meeting of the Council of The Society on 17 March 1990 (Exhibit WITN6392082); Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083); Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084); Minutes of the Executive Committee of The Society on 16 June 1988 (Exhibit WITN6392085); Minutes of the Executive Committee of The Society on 8 September 1988 (Exhibit WITN6392086); Minutes of the Executive Committee of The Society on 10 November 1988 (Exhibit WITN6392087); and Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).

m. Group Liaison and Training working party (as noted in Minutes of Society's Executive Committee meeting on 14 September 1989 (Exhibit WITN6392076B); Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); Minutes of the meeting of the Council of The Society on 18 March 1989 (Exhibit WITN6392080); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081); Minutes of the meeting of the Council of The Society on 17 March 1990 (Exhibit WITN6392082); Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084); Minutes of the Executive Committee of The Society on 8 September 1988 (Exhibit WITN6392086); Minutes of the Executive Committee of The Society on 10 November 1988 (Exhibit

WITN6392087); and Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).

n. Sales working party (as noted in Minutes of Society's Executive Committee meeting on 14 September 1989 (Exhibit WITN6392076B); Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); Minutes of the meeting of the Council of The Society on 18 March 1989 (Exhibit WITN6392080); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081; Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083); Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084); Minutes of the Executive Committee of The Society on 16 June 1988 (Exhibit WITN6392085); Minutes of the Executive Committee of The Society on 8 September 1988 (Exhibit WITN6392086); Minutes of the Executive Committee of The Society on 10 November 1988 (Exhibit WITN6392087); and Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).

o. Overseas working party (as noted in Minutes of Society's Executive Committee meeting on 14 September 1989 (Exhibit WITN6392076B); Minutes of the meeting of the Council of The Society on 28 November 1987 (Exhibit WITN6392078); Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); Minutes of the meeting of the Council of The Society on 18 March 1989 (Exhibit WITN6392080); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081); Minutes of the meeting of the Council of The Society on 17 March 1990 (Exhibit WITN6392082); Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083); Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084); Minutes of the Executive Committee of The Society on 16 June 1988 (Exhibit WITN6392085); Minutes of the Executive Committee of The Society on 10 November 1988 (Exhibit WITN6392087); and Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).

p. Research grant applications working party (as noted in Minutes of Society's Executive Committee meeting on 14 September 1989 (Exhibit WITN6392076B); Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); Minutes of the meeting of the Council of The Society on 18 March 1989 (Exhibit WITN6392080); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081);

Minutes of the meeting of the Council of The Society on 17 March 1990 (Exhibit WITN6392082); Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083); Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084); Minutes of the Executive Committee of The Society on 16 June 1988 (Exhibit WITN6392085); Minutes of the Executive Committee of The Society on 8 September 1988 (Exhibit WITN6392086); Minutes of the Executive Committee of The Society on 10 November 1988 (Exhibit WITN6392087); and Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).

q. Blood products working party (as noted in Minutes of the meeting of the Council of The Society on 28 November 1987 (Exhibit WITN6392078); Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); and Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083).

r. Group Liaison working party (as noted in Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081); Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083); Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084); Minutes of the Executive Committee of The Society on 16 June 1988 (Exhibit WITN6392085); and Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).

s. Seminar working party (as noted in Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079); and Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083).

78. The following paragraphs set out a selection of documents that illustrate key reforms that occurred within The Society's structure. This is by no means an exhaustive list of documents showing the various organisational changes that occurred in The Society's long history, but it helps to provide an overview of the changes.

79. There was reform that took place in 1984 which entailed the appointment of *"Society Representatives"* not otherwise covered by a local group. Minutes of the meeting of the Council of The Haemophilia Society on 15 September 1984 (Exhibit WITN6392068) record under the heading "Matters from this morning's session" at page 4:

> *At the morning session detailed consideration had been given to a paper submitted by the Executive Committee regarding the creation of a new structure which would entail the appointment of "Society Representatives" in local areas not otherwise affectively covered by a local Group. It was proposed by That "Society Representatives" may be appointed:*
>
> *(i) in areas where no local Groups exist, and*
> *(ii) for Haemophilia Centres where there is no formal Society representation.*
>
> *This was seconded by Mrs Guy and agreed unanimously. The Co-ordinator was asked to prepare a further paper dealing with functions, areas of jurisdiction, etc, to be circulated to all Council members.*

80. The Chairman's statement in The Society's 1989 Annual Report (Exhibit WITN6392033) at page 4 notes that there was a review of The Society as an organisation to assess its efficiency and use of limited resources available to it by the Charities Effectiveness Review Trust ("CERT"). The Chairman explained:

> *Another notable development was the review of the organisation to assess our efficiency in the use of the limited resources available to us. We saw the need for an objective appraisal and were fortunate in securing the assistance of the Charities Effectiveness Review Trust (CERT) for this professional assessment. CERT considered the Society to be a successful and healthy organisation but was able to offer some very constructive suggestions for maintaining and developing the Society's work in the future. As a result of this advice we shall, for instance, devote more of our resources to "member services" and to the local Groups of the Society.*

81. Minutes of a meeting of the Council of The Haemophilia Society on 29 October 1989 (Exhibit WITN6392089) record that the Council had spent the weekend discussing the "CERT report, along with the Executive Committee recommendations, in some detail". The minutes record at pages 1 to 2:

> *Those proposals had all been received with much enthusiasm and it was therefore put by the Chairman that the Council receive the CERT report and approve the recommendations for action and implementation by the Executive*

> *Committee. This was agreed unanimously. The Chairman stressed his delight at the willingness of Council to accept this change in the structure and management of the Society and hailed it as the beginning of a new era in the life of the Haemophilia Society.*

82. The March 1990 edition of The Bulletin (Exhibit WITN6392090) reports at page 1 in an article titled "C.E.R.T reports on our organisation" that CERT examined The Society and presented its report in August 1989. A full account of the report and The Society's response appears in the same edition of The Bulletin at page 8 in an article titled "The Society's first Chairman's Conference maps out our route into the 1990s: The CERT Report".

83. Minutes of a meeting of the Council of The Society on 17 March 1990 (Exhibit WITN6392082) record under a heading "CERT: Implementation" at page 2 that new Committee structure had been established for the Resources Committee, Policy Committee, Member Services Committee and Grants Committee.

84. In the Society's 1990 Annual Report (Exhibit WITN639034) Chairman Reverend Alan Tanner reported that The Society, *"had taken seriously the recommendations made by the Charities Effectiveness Review Trust (CERT) to help us use our resources as efficiently as possible. In common with other Voluntary Organisations, we have studied carefully the way in which professional staff and members of the Executive Committee may bring together their various skills and experience for the benefit of the organisation as a whole."*

85. Minutes of an Executive Committee meeting on 5 October 1991 (Exhibit WITN6392006) records the reasons for the restructure and the impact of the HIV campaign had on the organisations:

> *At the invitation of the Chairman, Mr Cowe said that the advances under consideration were all part of a continuing process started by CERT. The Society needed to "stock take" and look at its current position in relation to the headings laid down in the CERT Report and then to decide on the next step. Furthermore, the weekend was of value in its own right for the promotion of discussion and contacts between Committee members.*

> *Mr Dickason added that while the compensation campaign had given the Society a vision, it was perhaps time to renew and strengthen that vision. He felt that a re-evaluation was needed; the Society was in existence primarily to serve people with haemophilia, the membership and the Groups, and the Society's vision of how this could best be done needed a fresh appraisal. Such a process could give the Society a feeling of collective ownership, and provide a renewal of faith and purpose.*

86. Minutes of a meeting of the Council of The Haemophilia Society on 24 November 1991 (Exhibit WITN6392091) record under a heading "The Chairman's Residential Weekend" at page 5 that The Society agreed to engage an external agency, Compass Partnership to undertake a strategic planning process for The Society:

> *The Chairman raised the subject of the Society's proposal to embark upon a strategic planning process with the help of a professional organization, Compass Partnership. This had been introduced to the Council on the previous day, Saturday 23 November, when Mr Dickason had outlined what it might mean and what it could entail. Compass Partnership would assist the Society in the identification of goals and possible future directions and trends. It would help in the development of an overview of the work of the Society, enabling it to take a considered and measured approach to those issues affecting the lives of people with haemophilia. The estimated cost was £10,000. The Chairman recalled the engaging of CERT and although that had cost a smaller amount, it had at the time seemed large; the Council's decision to go ahead had been made with some trepidation. The Society had, however, benefitted enormously from the CERT recommendations, and the Chairman felt that while the sum presently under discussion might seem a large figure, the Society stood to acquire once again great advantage working with external professionals. After some discussion it was proposed by Mrs Dickson and seconded by* GRO-A *that the Society proceed with the strategic planning process in conjunction with Compass Partnership. This was agreed unanimously.*

87. Minutes of a meeting of Executive Committee on 16 May 1992 (Exhibit WITN6392092) record under the heading "Strategic Planning" at pages 6 to 8 discussion and decisions made about the Strategic Planning Groups proposals.

88. Minutes of a meeting of the Council of The Haemophilia Society held on 6 June 1992 (Exhibit WITN6392093) record under the heading "Strategic Planning" at page 2, the steps that were taken in relation to strategic planning supported by Compass Group.

89. Minutes of a meeting of the Council of The Haemophilia Society held on 21 November 1992 (Exhibit WITN6392094) record under the heading "Report from Strategic Planning Group" at page 3 that members had responded to a questionnaire; and this had *"provided useful information"* for the development of a new strategic plan.

90. Minutes of a meeting of the Executive Committee held on 1 July 1993 (Exhibit WITN6392095) record at page 2 that the Chairman introduced plans for a new structure to The Society's committees saying that "*through the Strategic Planning Process, with its review of the way in which the Society carried out its work, it had been determined to reduce the number of sub-committees from three to two. Committee A would deal with the internal aspects of the Society's activities, and Committee B would look after external affairs. Terms of reference in draft for each Committee had been circulated previously. The Chairman asked Mr Milne and Mr Cowe to comment."*

91. Minutes of a meeting of the Executive Committee held on 29 July 1993 (Exhibit WITN6392096) record at page 3 the Terms of Reference for Committees A and B; Rules of Procedure for Executive Committee and its Sub-Committees, including their structure and specific rules for the sub-committees.

92. Minutes of a meeting of the Council of The Haemophilia Society held on 20 November 1993 (Exhibit WITN6392097) record under the heading "Executive Committee Report" at page 2 that Andy Cowe outlined the environment that The Society had changed since the 1970s and 1980s and the factors that led to a new Strategic Plan. The report records:

> *Towards end of 1980s Haemophilia Society went through a period of uncontrolled growth. It was easy to raise money and the Society worked on the principle that it could do anything. Things have changed and the Society was trying to be all things to all people and spreading itself too thinly. This lead to the Strategic Planning Process which identified priorities for the Society. As a logical progression from the Strategic Plan, the Executive Committee structure, staffing and premises were of the Society reviewed to make sure that the*

organisation was equipped to carry out the strategies and challenges over the next few years.

93. The December 1995 edition of The Bulletin (Exhibit WITN6392098) informs us that there would be structural changes to The Society, including a new Memorandum and Articles of Association which was intended to bring The Society *"up to date in meeting modern Company and Charity laws".*

Question 5: Please provide a list of individuals who held decision-making roles in the Haemophilia Society from 1970 to 2000.

94. Exhibit WITN6392099 is a spreadsheet detailing trustees and members of the Executive Committee from the 1950s to 2019. This information was originally provided to the Inquiry on 11 July 2019 in response to a separate Rule 9 request and has subsequently been updated for the purpose of this Rule 9 response. Unfortunately, there are some gaps in the information, but I know that Society employees have tried to pull together as much information as possible from those documents that are available.

Question 6: Without providing any information by which individuals may be identified, did any of the individuals holding decision-making roles in The Society in the 1970s and 1980s have a personal interest in the matters being addressed by the Inquiry?

95. 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 HIV, Hepatitis C or both; Hepatitis B, Hepatitis D, vCJD 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.

96. 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 [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.

97. 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.*

98. In his witness statement dated 25 February 2021 [WITN4503001], the late Jonathan Cooper (The Society's AIDS Co-ordindator 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 bereminded 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.*

Question 7: Please describe the Haemophilia Society's involvement in any other inquiries, investigations or criminal/civil litigation in relation to the human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products.

99. The Society has never been party to any criminal or civil litigation in relation to the human immunodeficiency virus and/or hepatitis B virus and/or hepatitis C virus infections and/or variant Creutzfeldt-Jakob disease 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. I have set out below a number of documents which might assist the Inquiry's understanding in this regard.

100. The Society's position in relation to pursuing litigation on behalf of its members was set out at pages 7 to 8 of its 1986 Annual Report (Exhibit WITN6392030) as follows:

> *We have taken legal advice about the position of people with haemophilia who are known to be 'HIV antibody positive', an indication that they have been in contact with the virus. Many of those in this category experience serious disadvantages regarding employment, life insurance and mortgages, as well as in their general social relationships.*
>
> *It is clear from the advice we have received from Counsel that there is no case that the Society can pursue on behalf of our members, either corporately or individually. As each individual's circumstances are different it would be necessary for them to discuss their particular position with a solicitor before it can be established whether it is worth pursuing such an action through the Courts. While we sought this advice generally, and not based on any particular set of personal circumstances, we have to say that, on present known facts and upon our judgment of the advice we have received, the prospect of the majority of the claims succeeding is remote. There are two important reasons for this: the difficulty of proving negligence and the difficulty of identifying the proper body or person from whom compensation might be sought.*
>
> *Meanwhile, we are continuing to present to the Government the very special needs of people with haemophilia with regard to such matters as life insurance and mortgages. We shall press for some special recompense for the benefit of our members who have been diagnosed as 'HIV positive'.*
> *[D096389_000422019-0041]*

101. A Briefing paper on Haemophilia & AIDS prepared by The Society dated October 1989 (Exhibit WITN6392100) 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.

102. In its 1989 Annual report (Exhibit WITN6392033) The Society reported on its campaign to lobby government to settle claims out of court as follows:

> *The greatest concerns facing the Society for the past seven years have been associated with HIV infection acquired through the use of contaminated factor VIII. Despite the creation of the Macfarlane Trust in 1988 to meet the immediate needs of people with haemophilia and HIV, The Society has always been of the view that those who had been so tragically infected should have a measure of control over their own financial affairs.*
>
> *It was with this in mind that a campaign was launched during 1989 to persuade the Government to settle, out of Court, the many claims for compensation which had started in the High Court. This disaster – the greatest tragedy in the history of the National Health Service – demands the utmost compassion by Government. While their immediate response with a grant of £24m, to enable each infected person with haemophilia to receive £20,000, was welcome, it did not meet the main thrust of the campaign.*
>
> *The Society was fortunate in having the services of GJW Government Relations, who made an invaluable contribution of free advice and manpower. Many MPs from both sides of the House gave their support and thanks are most especially due to Robert Key, Frank Field, Patrick Cormack, Jack Ashley, Alf Morris, Geoffrey Johnson-Smith, Emma Nicholson, John Hannam, Sir Michael McNair-Wilson, Sir Bernard Baine, Sir Russell Johnson and John Marshall for their encouragement. The help of The Sunday Times was also important and greatly valued.*

103. It may be helpful to draw to the Inquiry's attention to (Exhibit WITN6392101), which appears to be a briefing for a meeting between the Prime Minister, and Robert Key and Society representatives regarding Haemophiliacs with HIV infection, dated 22 November 1989:

> *Out of Court Settlement*

> *8. We know the Haemophilia Society were advised around March 1987 against pursuing legal action. They are however pressing for compensation out of court, and have suggested that a settlement of £86m would be appropriate; this would average about £71,000 per case. Any out of court settlement of the litigation would carry with it a tacit admission of negligence and could set an unacceptable precedent by implying NHS liability for treatment which reflects the best available medical information at the time but turns out later to be wrong. The implication of liability could also undermine the medicines licensing system. The Licensing Authority (i.e. UK Health Ministers) and the Advisory Committees have been involved in a number of court actions. They have consistently denied liability and resisted any moves towards any out of court settlement. Any such move could encourage further litigation and expectations of similar settlements. Constant litigation would be damaging to the integrity of the licensing system, could lead to over defensive licensing decisions and could lead to problems in attracting members to sit on advisory committees. For these reasons Health Ministers are not considering an out of court settlement. Legal advice is that it would be inappropriate to comment on whether the Government is prepared to consider compromising the court proceedings by offering an out of court settlement.*

104. On 3 November 1990, Andy Cowe wrote to the then Secretary of State, The Rt. Hon. William Waldegrave MP (Exhibit WITN6392102):

> *…I also want to take this opportunity to correct some false impressions which appear to be present within the thinking of the Department in relation to people with haemophilia and HIV who are seeking compensation. The most serious of those relates to the fact that it has been alleged from within the Department that 'The Haemophilia Society' has named an acceptable sum for an out of court settlement. This is not the case: our position is very simply this - we have not, nor do we intend to, put forward a settlement figure. Proposals of this nature are entirely for the lawyers acting for those plaintiffs who are pursuing a claim for legal compensation. It must also be pointed out that those who are pursuing this course are doing so at the behest of the Government who have, again and again, insisted that this was the only course available to those seeking compensation: those who have chosen this route have done so because of Government policy.*

> *It has been open to the Government since 1986 to settle this matter in an open-handed manner without the need for litigation: the matter only became one of public and political interest because of the piece meal fashion in which the Government has chosen to deal with it. Contrary to the view which has been expressed by the Department in recent weeks I would want to quietly remind you that the payments which have so far been made to the Macfarlane Trust have only been made as a result of very hard campaigning by ourselves. This, in turn, generated widespread political and public support. It is also surprising that, in recent weeks, those 'ex-gratia' payments have suddenly become payments made from a sense of moral responsibility.*
>
> *We believe that there is a great deal to be gained on both sides by an out of court settlement - not least for people with haemophilia themselves: they are currently dying at the rate of at least one a week and that, of itself, is a telling factor about the overall urgency of our unique situation. However, more importantly for you, and for the Department, it would mean that a settlement could be made without any admission of liability for negligence. It is also, in our view, most unfair that the Department should continue to make direct comparisons between people with cancers, heart conditions, renal failures, etc; and people with haemophilia and HIV. None of those people acquired -their condition as a result of treatment prescribed by the NHS. It is this fact which makes the position of our affected members so tragically unique. We are deeply concerned that there now appears to be little or no negotiating taking place between yourselves and the plaintiff's lawyers. We are giving active consideration to the possible role of an intermediary to look at a constructive way out of the impasse which exists between the two sides. We would welcome your early response to this suggestion so that the matter might be progressed if you feel that it would be helpful.*

105. 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.*

106. The Society's position in relation to the Hepatitis C litigation was stated to its members in the March 1995 edition of The Bulletin (Exhibit WITN6392103) at page 5 in an article titled "*Hepatitis C Litigation – Time Limits for Making Claims*":

> *The Haemophilia Society can neither encourage nor discourage individuals from pursuing litigation (and certainly cannot advise on merit of any individual case) but the Society feels it important to point out that those who are considering a possible claim for medical negligence, should not delay in seeking advice in view of the strict time limits which apply to such claims.*
>
> *The following advice has been received from a leading firm of solicitors experienced in haemophilia litigation, with regard to time limits:*
>
> > *"There may be people with haemophilia infected with hepatitis C virus who are considering legal advice concerning a possible claim for medical negligence. If you are in this position, you should not delay in seeking advice in view of the strict time limits which apply to such claims.*
> >
> > *By law, if a person has been "injured" as a result of medical negligence, then a claim must be made within 3 years of the date of the "injury" [this] is the date of infection with hepatitis C. Most people are completely unaware of having been [in]fected at that time. In such cases, the three year time period does not begin until the date that they first became aware that they have been infected. This will usually be when a person is informed of a positive result."*

> *Individuals concerned may contact a lawyer of their choice and the Society has a list of solicitors currently involved in hepatitis claims.*
>
> *Individuals in receipt of treatment in Scotland and Northern Ireland should please bear in mind that advice should be sought in their respective countries."*

107. 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 WITN6392104). 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.

108. The Society's summer 2001 edition of The Bulletin (Exhibit WITN6392105) refers to 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. The minutes of the Campaign Supporters meeting dated 4 November 2005 (Exhibit WITN6392106) records that the call for an independent public inquiry was discussed. It appears from the document that the group made 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*".

110. The Society's publication "H3" dated July 2006 (Exhibit WITN6392107) 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…*

111. 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."*

112. I have seen minutes of the Campaign Supporters meeting dated 4 November 2005 (Exhibit WITN6392106). 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".

113. In 2008, The Society made submissions to the independent 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, its consequences for the haemophilia community and others affected: and further steps to address both their problems and needs and those of bereaved families'* [ARCH0001232]. The Society also made a second submission to the Archer Inquiry (Exhibit WITN6392108).

114. The Society was actively involved in the Scottish Public Inquiry that was set up by Scottish Ministers under the Inquiries Act 2005 in January 2009, chaired by The Right Honourable Lord Penrose which investigated Hepatitis C/HIV acquired infection from NHS treatment in Scotland with blood and blood products ("the Penrose Inquiry"). The Society (along with Haemophilia Scotland) were patient interest organisations designated as core participants and were represented by the same solicitors in the Penrose Inquiry (see further Final Report: Appendix 3 - Core Participants (penroseinquiry.org.uk) The submissions and documents set out below were submitted to the Penrose Inquiry on The Society's behalf.

  a. TOPIC B1 The efforts made to discourage 'higher risk' donors from giving blood (by the dissemination of information, including leaflets); whether these efforts went far enough and began early enough: (Exhibit WITN6392109)

  b. TOPIC B2 The use of blood product concentrates in Scotland, including any perceived disadvantages of such products, from their introduction in or around 1974; the continuation of the use of commercial concentrates in particular after: (Exhibit WITN6392110)

  c. TOPIC B4 The decision not to use kits from the United States of America for testing donated blood for the virus as soon as they became available but, instead, to follow a process of evaluation of the kit before any such use: (Exhibit WITN6392111)

  d. TOPIC B5 The information given to patients (or their parents) about the risk of AIDS before their treatment with blood or blood products: (Exhibit WITN6392112)

e. TOPIC B6: The effects of infection with HIV, including the effects of treatment, on patients and their families: (Exhibit WITN6392113])

f. TOPIC C1 The acceptance of blood from ‘higher risk’ donors, in particular: C1a) prisoners; and C1b) donors who had a history of jaundice, and who were negative for Hepatitis B when the existence of Non-A Non-B Hepatitis was known and its presence could not be excluded: (Exhibit WITN6392114)

g. TOPIC C2 The non-introduction in Scotland of surrogate testing for Non-A Non-B Hepatitis: (Exhibit WITN6392115)

h. TOPIC C3A The use of blood product concentrates in Scotland in the period between the introduction of NHS heat treated products in 1984 and the supply of NHS products sufficiently treated to inactivate Hepatitis C: (Exhibit WITN6392116)

i. TOPIC C4 The interval between the availability of tests for the Hepatitis C virus in 1989 and the introduction of screening of donated blood for the virus in the United Kingdom in September 1991: (Exhibit WITN6392117)

j. TOPIC C5A The information given to patients (or their parents) about the risk of non-A non-B Hepatitis and the severity of the condition before their treatment with blood or blood products: (Exhibit WITN6392118)

k. TOPIC C6 The effects of infection with Hepatitis C, including the effects of treatment, on patients and their families: (Exhibit WITN6392119)

l. The List of Issues for the Patient Interests Core Participant Group: (Exhibit WITN6392120)

m. Submissions on statistics: (Exhibit WITN6392121)

n. Additional submission on statistics: (Exhibit WITN6392122)

115. The Haemophilia Society prepared a response to the Penrose Inquiry report: (Exhibit WITN6392123)

Section 2: Relationship with members

Question 8: Please describe how membership of the Society was structured, in particular was there one membership rate/type or different rates/types of membership according to whether there was one or more members of a family with haemophilia?

116. More than 36,000 men, women and children in the UK have a diagnosed bleeding disorder, and this number rises every year. As at 31 March 2022, our membership numbers were 4,717 members of The Society. This includes people and families living with bleeding disorders, bereaved relatives of people with a bleeding disorder as well as healthcare professionals. Everyone affected by a bleeding disorder is welcome to join as a member, including people living with a bleeding disorder, their friends and family, healthcare professionals, doctors and nurses. Membership to The Society is free and open to all. One can see immediately that currently, The Society membership comprises less than 12% of the national population of people with a diagnosed bleeding disorder. In the past, a much higher proportion of those with a diagnosis were members (see the paragraphs below). The different numbers now probably reflect the fact that people with bleeding disorders live much longer lives and have the benefit of treatment that enables them to live with many fewer restrictions so that they may feel less need for membership.

117. Historically, membership structure, access and rates varied. Set out below are documents and evidence which record historical membership rates.

118. Minutes of a meeting of the Council of The Haemophilia Society on 24 October 1970 (Exhibit WITN6392124) record that there was discussion about raising the subscription fee for members:

> *Dr. Kuttner asked whether it would not be opportune for the sub-scription to the Society to be raised. The Treasurer said that many members already sent a donation with their subscription and after some discussion the matter was left in abeyance.*

119. I understand from the Minutes of a Special General Meeting of The Society on 22 November 1975 (Exhibit WITN6392125) that the subscription fee at the time was 5 shillings.

120. Minutes of a Special General Meeting of The Society on 22 November 1975 note that the purpose of the meeting was to consider an alternation of the Rule requiring an annual subscription of five shillings. At this meeting, the Honorary Secretary read and proposed a resolution (of which the required prior notice had been given to members) to amend Rule 3(a) to read: *"Membership shall be open to anyone on payment of the annual subscription which shall be determined from time to time by the Council and which shall be payable on the first day of January in every year."* This was seconded by the Honorary Vice Chairman. The document then records the need for this change as follows:

> *The subscription had been unaltered since the Society's registration over twenty-five years ago and if the resolution was passed, Council proposed to increase the subscription as at present it did not even cover the cost of posting the News Bulletin. It was felt better in future to leave the sum to be determined from time to time by the Council rather than have to hold further Special General Meetings when an increase was needed in future. He also reminded the Meeting that the subscription was a minimum requirement and a donation could be and often was added to this by members. A large number at present donated 75p with their subscription. He reminded members that those unable to pay could retain their membership by making a simple declaration of their inability on the membership form. The proposal was then put to the Meeting and adopted by an overwhelming majority.*

121. Minutes of the Annual General Meeting of The Society held on 25 April 1976 record that there was an increase in The Society's annual subscription to £1. (Exhibit WITN6392126).

122. The first edition of The Society's Bulletin in 1985 records at page 7 that membership fees increased to £5 (Exhibit WITN6392127).

123. Minutes of the Executive Committee on 2 May 1995 (Exhibit WITN6392128) record the following discussion about Society membership:

> *It was agreed that the definition of members needs to be clarified and that we need to decide which model of membership to adopt. Ms Piper's interpretation of the current situation is that everyone is a legal member of the company. Mr Cowe presented the three options for discussion:*

> i) ***All members are members of the company:*** *This is the current situation.*
>
> ii) ***Ruling Oligarchy:*** *Only the Trustees are members of the Company*
>
> iii) ***Two tier membership:*** *The membership could be split into a two tier membership to identify those who would want to have the right to vote and those only wishing to receive the Society's publications.*
>
> *The Committee preferred the third option above. There should not be an option for free membership for people or organisations only wishing to be on the mailing list.*

124. Minutes of an Executive Committee meeting on 13/14 October 1995 (Exhibit WITN6392129) record that there were *"planned changes to membership fees. The subscription for the first membership in each household will be £10, and for each additional member the fee is £5. There will also be a targeted campaign to remind people about their renewal fees. Mr Dolan enquired what would happen if members do not want to pay the increased fee and leave the Society. Ms Archer replied that there is a trend that individuals pay more than £5 anyway so many are unlikely to be affected by the changes. There will also be a drive to increase deed of covenants. Mr Taylor suggested that the Society be more pro-active in increasing the number of member donors e.g. through haemophilia centres."*

125. David Watters comments at paragraph 13 of his statement dated 18 January 2021 in relation to access to membership and fees: [WITN3429001]:

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

126. The Minutes from a Trustee meeting on 30 November 2000, (Exhibit WITN6392130) state:

> *c) Membership rates for 2001*
>
> *Karin Pappenheim spoke to the paper. Following discussion, it was proposed by Simon Taylor and seconded by Alex Susman-Shaw that:*
>
> *"membership rates for 2001 be amended as follows:*
>
> - *Voting – £16 per year*
> - *Subscriber – £10 per year*
> - *Fee waived for unwaged people – free*
> - *Overseas subscriber – £20 per year (unless hardship)*
> - *Corporate subscriber – £28 per year*
> - *Additional voting adult at same address £5 per year (unchanged)"*
>
> *AGREED NEM COM*

127. The Minutes from a Resources sub-committee Meeting on 13 November 2003 (Exhibit WITN6392131) note that it was agreed that membership rates would increase for the following year:

> ***Membership rates** – to agree the increase for next year*
>
> *Trustees agreed to increase the current full membership rate from £16 to £18; subscriber rate from £10 to £15; overseas rate from £20 to £22. It was **AGREED** to look in 2004 at combining them into one main subscription by 2005.*
>
> *It was also **AGREED** that young people reaching the age of 16 be given free membership of the Society until they reach 21.*

128. The Society's Spring 2007 edition of "HQ" magazine notes at page 3 that in 2008 (Exhibit WITN6392132), membership rates dropped:

> *MEMBERSHIP RATES DROP FOR 2008!*
>
> *The Society is continually trying to reach everyone in the bleeding disorders community. We are aware that there could be many out there who feel restricted by the cost of the membership subscription and confused by the various membership options. We have therefore decided to lower the*

subscription rate and simplify our membership categories as from 1 January 2008.

Our new membership rates from 1st January 2008 will be:
- *Full individual member with voting rights (Member) = £10 per annum (previously £18 per annum)*
- *Youth member (up to 18 years old and extended to those in full time education) = Free*
- *Overseas subscriber = £25*
- *Fee waived = Free for those on income related benefits*

We will no longer have the subscriber categories or additional members/subscribers, therefore everyone over the age of 18 who becomes a member will have the right to vote in elections or for special resolutions. For two members at the same address, the full membership subscription of £10 each must be paid. A separate mailing to each member is available upon request.

We hope you will continue to support us and perhaps decide to give an additional donation towards the various areas of our work:

Research • Children's activities • Fundraising • Events • Publications Women Bleed Too project • Youth project • Hardship fund • Telephone Helpline

For those who are already paying by standing order, a new standing order form is available on request should you wish to amend your order. Your support is very important to us and if there is any way that we can improve our services, please don't hesitate to let us know.

129. From 2012, membership fees were stopped and since that time The Society is free to join for all members and they retain full voting rights.

Question 9: Please provide membership numbers of the Haemophilia Society since 1970.

130. As noted above, as at 31 March 2022, our membership numbers were 4,717 members. This includes people and families living with bleeding disorders, bereaved

relatives of people with a bleeding disorder as well as healthcare professionals. Historically, membership numbers have varied.

131. The Society does not hold records of exact membership numbers from year to year, however, I have set out below a number of documents which set out membership numbers at various points in time and which may assist the Inquiry with this question.

132. David Watters comments at paragraph 13 of his statement dated 18 January 2021 [WITN3429001] that "*In February 1983, it* was *reported in the Group Seminar Proceedings that there were 5,000 individuals with haemophilia in the UK and only 1,500 of those were members of The Society [WITN3429004/PRSE0003074].*"

133. The results of a 1986 "Treatment Survey" (Exhibit WITN6392132) report in the section "Survey Method" at page 1 that there were about 3,000 people on The Society's mailing list at the time and that 2,000 of these addresses are those of haemophiliacs or their families.

134. The Society's 1992 Annual Report notes that membership numbers reached 4,500 (Exhibit WITN6392143).

135. The Society's 2003 Annual report notes that there were 4,800 members registered (Exhibit WITN6392040).

136. The Society's 2010 Annual report notes that there were over 4,000 individual members: (Exhibit WITN6392047) .

137. The Society's 2013 Annual report notes that there were over 4,300 members: (Exhibit WITN639250).

138. The Society's 2017 Annual report states that membership number increased from 5,435 to 5,597 that year: (Exhibit WITN6392054).

139. I note that in 2018, The Society performed a "clean-up" of its database following the introduction of the EU General Data Protection Regulation. We contacted all members on our database and asked people to confirm whether they wanted to be a member. This exercise identified a number of repeat entries, therefore, membership numbers dropped following this period.

140. The Society's 2019 Annual report states that there were just under 5,500 members: (Exhibit WITN6392056).

141. The Society's 2021 Annual report states that there were over 4,000 members: (Exhibit WITN6392058).

Question 10: What benefits have been provided to members by the Haemophilia Society from 1970 to 2000? Please explain how if at all the benefits provided have changed over that time period.

Historically, the benefits offered to members have varied. By way of example, set out below are a selection of editions of The Bulletin in which record examples of member benefits:

a. The Bulletin No. 1 1979 (Exhibit WITN6392144) at page 3 under the heading "Haemophiliacs – The question of driving licenses and motor car insurance", which records an Executive Committee member (Mr David Rosenblatt) offering advice in relation to motor car insurance;

b. The Bulletin No. 1 1979 (Exhibit WITN6392144) at page 6 under the heading "Your problems: Your letters answered by Vicki Stopford", which records a social worker (Vicki Stopford) providing advice to members;

c. The Bulletin No. 1 1979 (Exhibit WITN6392144) at page 7 under the heading "Annual General Meeting" notes that The Society's Annual General Meeting would include a panel discussion, during which members will have the opportunity to ask questions on the subject of "Psychological Problems relating to Haemophilia;

d. The Bulletin No. 1 1980 (Exhibit WITN6392145) at page 5 under the heading "The treatment of haemophilia" records that pamphlets on various aspects on treatment of haemophilia were available to members;

e. The Bulletin No. 2 1985 (Exhibit WITN6392146)

f. The Bulletin No. 3 1995 (Exhibit WITN6392147) records at page 2 under the heading "Publications and Services available from the Haemophilia Society", a list of services available to members;

g. The Bulletin No. 3 1998 (Exhibit WITN6392148) at page 2 records a list of services available to members;

h. The Bulletin No. 1 2000 (Exhibit WITN6392149) at page 2 notes The Society's free information and advice helpline;

142. The March 1995 edition of The Bulletin (Exhibit WITN6392103) sets out the publications and services that were available from The Society at the time:

Publications and Services available from the Haemophilia Society

Publications

- *The Society produces the range of books, booklets and leaflets listed below to help people with haemophilia.*
- *Introduction to haemophilia*
- *Joint Care Exercises*
- *Hepatitis*
- *The Essentials of Haemophilia care*
- *Teaching Children with Bleeding Disorders*
- *NHSME Patient Perspective Booklet*
- *Past copies of the Bulletin*

Services

- *The Society works to help people with haemophilia from, its national office and also via the local Groups. The services currently available from the national office are:*
- *Support to children and families affected by HIV and haemophilia*
- *Information and help with benefits, in particular Disability Living Allowance*
- *Hardship grants*
- *Armourpage service*
- *Caravan holidays*
- *Adventure holidays for children*
- *Fun-raising support*
- *Assistance with media enquiries*
- *Information on treatments and blood products*
- *Travel insurance advice*
- *Information on travel regulations/restrictions*
- *Haemophilia Days*
- *One-off meetings on specific issues, such as hepatitis*

143. Historically, various grants have also been given to members. Details of all sums given for grants are recorded in The Society's Annual Reports. As noted in the extract of David Watters' evidence above, The Society's "Case Committee" was a working party or sub-committee that would meet monthly to consider requests from members for monetary grants. An article at page 4 of the second edition of The Bulletin in 1987, "*Continuing our look at… The Working Parties: The Case Committee*" (Exhibit WITN6392150]) explains the work of the Case Committee:

> *In fact, this committee is about as old as The Haemophilia Society itself and came into existence when the Society was founded, as we were fully aware of the need to deal with cases of hardship and the disadvantaged amongst our own people.*
>
> *It is perhaps one of the least known, but most important, of our sub-committees. Since the start of the Society it has been our principle that help to and care of our own people comes long before any other assistance, whether it be research or anything of similar nature. We have tried always to live up this doctrine and over the years this has become a very important function of the Society.*
>
> *The Case Committee meets monthly and finds that each month many cases are awaiting its decision. The number of cases is growing continually and the amounts of money required are becoming quite a strain on the finances of the Society. What used to be a small demand on our resources a few years' ago is now approaching many, many thousands of pounds annually.*
>
> *No specific examples can be given (since the Case Committee's work is confidential) and no case is discussed or mentioned outside the Committee's meetings.*
>
> *Cases come to us from every part of the United Kingdom. They cover the need for telephones, re-training, transport, dietary assistance, domestic help (redecorating, refurnishing etc.) Most request come from single parents, widows or widowers, unemployed parents and at times, from old people, all of whom are either people with haemophilia, who have haemophiliac children – or have other blood-disorders such as V.W. The requests usually reach us via social workers or other official bodies.*

144. The grants made by the Case Committee are recorded in minutes of the meetings of The Society's Executive Committee. Set out below are a number of examples. The Society's documents show that the Case Committee was in existence in at least 1982 (see for example The Society 1982 Annual Report at page 7 (Exhibit WITN6392026), which states:

> *The Case Committee continued to meet regularly as a Sub-Committee of the Executive Committee, to consider requests to help people with haemophilia or their families. Applications were received from members themselves, their Social Workers or the officers of the Group concerned. Each request was considered with great care and we are grateful to the Chairman of the Case Committee, Mr. Jim Hunter, and its members for the time and sympathetic attention given to these applications. Sixty applications were received. Forty-seven payments were made from the Benefit Fund, totalling £2,821. In reaching decisions about individual applications, the Case Committee sought guidance from the social workers of the Centres involved and, where appropriate, from the officers of the Group. The Chairman of the Case Committee reported that, in this particular part of the Society's work for and with its members, we were expressing the fellowship which is one of our principal objectives.*

145. Further examples of the provision of grants can be found in the minutes of a meeting of the Executive Committee of The Society on 14 June 1983 (Exhibit WITN6392151) where it is noted at page 3 that the following grants had been agreed:

> ***CASE COMMITTEE:*** *The Co-ordinator reported on the meeting of the Case Committee which had been held earlier in the day. The following recommendations were made to the Executive Committee:-*
> *(a) A grant of £50 to enable a 21 year old haemophiliac to obtain employment.*
> *(b) A grant of £50 to assist a young family with general financial problems, on the recommendation of their social worker.*
> *(c) A grant of £50 to assist a young couple with their financial problems, again on the recommendation of their local authority social worker.*
> *(d) A grant of £50 to assist a haemophiliac and his problemed family with general expenses.*
> *(e) A grant of £40 to assist a couple who were having difficulty adjusting to unemployment and a series of bills.*

It was proposed by Mr. Milne, seconded by Mr. Prothero, that the Executive Committee approve these recommendations and this was agreed unanimously.

146. Minutes of the meeting of the Executive Committee dated 14 July 1983 (Exhibit WITN6392152) also provides examples of further grants being agreed on pages 3 to 4:

> ***CASE COMMITTEE:*** *The Co-ordinator reported that the Case Committee had met earlier in the day and wished to make the following recommendations to the Executive Committee:-*
> *(a) A grant of up to 50% of telephone installation costs for a member in Yorkshire conditional upon the social worker obtaining the balance from other sources.*
> *(b) A grant of £70 to enable a member to go on one weeks holiday with his family on the recommendation of his Centre Director.*
> *(c) A grant of £20 for clothing to enable a young member to take part in the North Wales Adventure Holiday.*
> *(d) A grant of £60 to assist a member in Wales with general financial problems arising from a complicated Benefit's situation - this upon Social Worker's recommendation.*
> *(e) A grant of £20 to cover travel costs to enable a young member to have a holiday.*
> *(f) A grant of 50% of telephone installation costs for a member conditional upon the balance being obtained from other sources.*
> *(g) To increase a grant of £50 agreed at the last meeting in respect of removal costs to £64.43.*
>
> *That the above recommendations be approved was proposed by Mr. Milne, seconded by Mrs.[REDACTD] and agreed unanimously.*

147. Minutes of the meeting of the Council of The Haemophilia Society on 14 March 1987 (Exhibit WITN6392065]) record:

> *(d) Case Committee: Dr Kuttner reported that since the last meeting in November the Case Committee had received between thirty and forty applications for grants and that grants totalling £3,500 had been made. In 1985*

> *the total of grants paid was £5,000 (approximately): in 1986 this figure rose to £9,800. Dr Kuttner explained that the Executive Committee had empowered the Case Committee to make grants of up to £300, without reference to the Executive Committee. The question of increasing the current limit on Groups (£50) was discussed but it was agreed that £50 was adequate to cope with emergency situations as they arose. Mr Prothero and the General Secretary stressed that grants could reach people in need within 48 hours of a request being received. Mrs Daniel (formerly Mrs Lewis) stated that she made many grant applications in the course of her work: she knew of no organisation which could match the Haemophilia Society on the speed with which decisions were made.*

148. Notes of the morning session of a Council meeting held on 17 September 1988 (Exhibit WITN6392153) record that the work of the Case Committee continued despite the Macfarlane Trust being in operation:

> *(c) <u>Case Committee</u>: Dr Kuttner reported that the work of the Case Committee had virtually returned to normal, now that the Macfarlane Trust was handling its own cases. In May the committee had handled some 30 cases, giving grants totalling £13,500 and in June some 82 applications had been considered resulting in awards of £26,500. Of those amounts some £5,000 was attributable to the Society. From July, the Trust had handled its own applications and the Case Committee had considered applications as follows: In July 15 grants totalling £1,600, in August 25 grants totalling £3,500 and in September one grant totalling £200.*
>
> *On average the Case Committee expected to deal with 15 grants in a month, totalling, £2,500 -£3,000.*
>
> *Dr Kuttner also stressed the increased number of applications from unemployed people and stressed the importance of education for people with haemophilia.*

149. The Case Committee is also referred to as a "working party" in the following minutes of meetings of The Society's Executive Committee and Council:

    a. Minutes of Society's Executive Committee meeting on 14 September 1989 (Exhibit WITN6392076B);

b. Minutes of the meeting of the Council of The Society on 16 April 1988 (Exhibit WITN6392079);
c. Minutes of the meeting of the Council of The Society on 18 March 1989 (Exhibit WITN6392080); Minutes of the meeting of the Council of The Society on 23 September 1989 (Exhibit WITN6392081);
d. Minutes of the meeting of the Council of The Society on 17 March 1990 (Exhibit WITN6392082);
e. Minutes of the Executive Committee of The Society on 7 July 1987 (Exhibit WITN6392083);
f. Minutes of the Executive Committee of The Society on 10 March 1988 (Exhibit WITN6392084);
g. Minutes of the Executive Committee of The Society on 16 June 1988 (Exhibit WITN6392085);
h. Minutes of the Executive Committee of The Society on 8 September 1988 (Exhibit WITN6392086);
i. Minutes of the Executive Committee of The Society on 10 November 1988 (Exhibit WITN6392087); and
j. Minutes of the Executive Committee of The Society on 10 January 1989 (Exhibit WITN6392088).

150. The Society's grant making function later moved from the Case Committee to the Member Services Committee. Minutes of a meeting of The Society's Executive Committee on 25 March 1993 (Exhibit WITN6392154) record The Society's grant making policy, under a heading "Member Services: policy on grants to members" at pages 5 to 6. This documents sets out the policy, process and practice for making grants to members.

Question 11: What are the structures and processes that are in place to enable members to influence decisions being made by the Society? Please explain how if at all these structures and processes have changed over time.

151. The Society sees itself as an organisation that listens to and acts on the feedback received from its members. We see ourselves as an open and approachable organisation. Our staff are regularly engaged with our members through social media, via email or at events. Being a small organisation, this is something that we pride ourselves on. We attend the Infected Blood Inquiry hearings and we are visible within our community and people know who we are. When strategic decisions are made, we

aim to bring members along the way and to hear their voices throughout the decision making process. We do so through regularly conducting surveys and seeking feedback from our members.

152. For example, we recently conducted a survey about members' views related to compensation. We received over 400 responses, which influenced our submission to Sir Robert Francis' Independent Compensation Framework Study on Compensation.

153. In 2021, we conducted a comprehensive survey into the impact of COVID-19 on the services received by our community from their centres during lockdown, and the wider impact on their health. The results were accepted for publication and were presented virtually at the European Association for Haemophilia and Allied Disorders clinical conference in February 2021. We repeated the survey in late 2021 to compare two separate years of data, providing insight into the impact of COVID-19 and changes to working practice and service provision.

154. Historically, The Society has also sought to include its members in decision-making and future planning through questionnaires and surveys. For example Minutes of the Executive Committee of The Haemophilia Society meeting, 4-5 October 1991 (Exhibit WITN6392061) record under the heading "Planning process proposal" that there was discussion of the merits and demerits of The Society embarking on a formal strategic planning process. The minutes record that: *"It was seen as crucial that the entire membership of the Society should be involved through a questionnaire and that a representative of local Groups should sit on the central planning committee — others might well have a role to play in project teams that would be engaged to explore particular aspects of the work of the Planning Brief"* As described below in this statement, the questionnaire was sent to members and the responses received informed The Society's new strategic plan.

155. All members also have voting rights to elect the Board of Trustees.

156. Historically, I understand that The Society also attempted to maintain a consultative relationship with its members.

157. For example, an important part of the structure of The Society was the Council of the Haemophilia Society. As mentioned above in the extract of paragraph 11 of David Watters' statement, The Council of The Haemophilia Society sat below the Executive Committee, which was the supreme decision making body of The Society. The Council

consisted of two representatives from each local group and it reported directly to the Executive Committee; members of the Executive Committee also attended the Council's meetings. Minutes of the Council of The Haemophilia Society are referenced throughout this statement and illustrate the key role that members played in influencing The Society's decision-making.

158. Minutes of the Executive Committee of The Haemophilia Society meeting on 14 November 1991 (Exhibit WITN6392155) record under the heading "Matters arising" at page 2 that David Watters reported on plans for the Chairman's Conference to be held in November 1991 and said that *"the occasion would be, amongst other things, an attempt to get local Groups to own and be part of the Society's strategic plans for the future. It was hoped, also, that the membership at large would be able to feel that they could play a greater part in the affairs of the Society and that they could have some effect on the decision and policy making processes in the coming year."*

159. At pages 12 to 13 of The Society's April 1994 edition of The Bulletin (Exhibit WITN6392156), there is a two page article by Graham Barker, Director of Services and Development titled "*What do members want from The Haemophilia Society*" with reference to a survey of what members wanted from the Society. The article's introduction states:

> *Last year the Society undertook a survey amongst the membership to try and find out what you felt about the services we currently offer and what you would like in the way of new services.*
>
> *As part of the Strategic Plan it was agreed that it was essential that the needs assessment exercise be carried out to find if there were groups within the membership that has specific needs that the Society should try to meet.*

160. Another historic document which illustrates The Society engaging with its members through surveys is the "Needs Assessment Progress Report" dated 9 July 1993 (Exhibit WITN6392157). This document explains:

> *1. As part of the Strategic Plan it was agreed that a needs assessment exercise would be carried out to identify the varying needs of people with haemophilia and their families. From this assessment, proposals for modified and new services would be developed with the intention of implementing them in 1994.*

> *2. Over the last few months questionnaires were sent out to 10 different categories of members covering 477 people (see appendix). In addition all members were informed of the questionnaire through Update and encouraged to ask for a copy. Copies were also made available at the AGM. The overall response rate was disappointing (about 25% but this varied between categories) given that we were asking people what they wanted and a free post envelope was provided. A reminder was sent to the first two categories and this produced a slight increase but it was decided that it was not worth repeating this for the other categories.*

161. In his witness statement dated 25 February 2021 [WITN4503001], Jonathan Cooper (AIDS Co-ordinator for The Society from 1987 to 1990) wrote about the central role that members played in The Society's work:

> *[21] The members were the key to the organisation. The membership always remained THS's priority. We were there to serve them. Linda was absolutely on top of the membership, which probably meant she was the next most important staff member after David. She and David knew everyone. It was really impressive to observe them with the membership and listen to them deal with membership issues. At that time, I think most people with haemophilia were members of the Society, certainly those with severe haemophilia.*
>
> *[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 finding for the position that I was to be appointed to.*

Section 3: Relationship with clinicians

Question 12: What role does the Society play in providing medical information to members? How, if at all, has that role changed over time?

162. 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.

163. We are aware that some of our members are angry and disappointed by actions taken by The Society in the past. During the early 1980s, The Society issued statements reassuring patients that the new factor treatments were safe and to continue using them. The information we gave our members was based on guidance from the UKHCDO and from the government.

164. 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, had been shown to be damaging to the community and incorrect. For this, we apologised unreservedly, see (Exhibit WITN6392158).

165. In its 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 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.*

166. Set out below are a number of historical documents which may assist the Inquiry in relation to this question in ascertaining the role The Society played in providing medical advice to its members.

167. Minutes of the Meeting of the Council of The Haemophilia Society on 17 September 1988 (Exhibit WITN6392066) record a report from the Blood Products/Treatment and Care working party report that *"John Barton (South Essex) urged Groups to place greater emphasis on the supply and the availability of treatment since this was, perhaps, the most important aspect of the Society's work. Ken Milne also reported additionally on the monoclonal product, reporting the reservations held by members of the Medical Advisory Panel expressed at the recent meeting with them.*

168. Minutes of a meeting of the Executive Committee on 13/14 October 1995 (Exhibit WITN6392129) record that there was some disagreement amongst the Medical Advisory Panel as to the purity of products:

> *The Society's policy on recombinant and high purity products cause some contention amongst the MAP panel. They felt the strong wording would frighten people unnecessarily, who were on intermediate purity products, particularly as in their opinion 8Y product is one of the best products available. Mr Taylor suggested re-wording the policy to 'the Society believes that Intermediate Purity products ought to be phased out'. This was agreed by the Executive.*

169. Currently, The Society produces a wide range of literature to inform patients, members and the general public about bleeding disorders and relevant policy issues such as contaminated blood support. We also provide links to useful publications from other organisations. However, The Society does not give out any medical, diagnosis or treatment advice. We recommend that members speak to their haemophilia team directly regarding any specific healthcare concerns.

170. The Society now has a Clinical Advisory Group ("CAG"). The Terms of Reference dated 27 January 2015 set out the purpose of the CAG:

> *The Society shall establish a Clinical Advisory Group (CAG)which shall be asked to advise on all aspects of treatment relevant to bleeding disorders. The Society shall ensure that all of its statements and publications on clinical issues are approved by an appropriate member of the CAG. Any advice received should be in a written (e-mail) form to ensure accuracy.*
>
> *For the avoidance of doubt, The Society shall be responsible for its own statements and publications.*
>
> *It is recognised that the United Kingdom Haemophilia Centres Doctors' Organisation (UKHCDO) is a key source for identifying and defining clinical best practice, and that the CAG should often be able to rely on published statements of the UKHCDO. The UKHCDO is invited to nominate a senior member to act as a liaison between it and the CAG.*

171. The CAG is now formulated so that we have access to input from a wide range of healthcare professionals not limited to consultants. We now have for example physiotherapists, nurses and health economists on the CAG. The Society will also go to EHC and WFH if we want specific advice. The Society is presently reviewing CAG's Terms of Reference to ensure that it is up to date and working properly.

172. The CAG reviews our publications (the website, booklets and leaflets) for clinical accuracy. Other than that, we seek advice from CAG, EHC or WFH would when we have a technical or medical question to which we do not know the answer. We might ask the CAG's opinion about something like Covid-19 vaccinations for people with bleeding disorders; Gene Therapy; or understanding the inheritance pattern of a rare bleeding disorder. Sometimes we might also ask questions for specific individuals. We would never give medical advice to our members. Information from CAG members on technical or medical queries would be used for internal purposes to advance the knowledge of staff. This might be for the purpose of, for example, writing a publication or suggesting questions for members to ask their doctors and nurses. For example, The Society's current Gene Therapy booklet is with the gene therapy working group (which includes CAG members) for review.

173. The current members of the CAG are:

Name	**Role**	**Centre**	**Expertise**
David Stephensen	Physiotherapist	Canterbury and Royal London	Musculoskeletal impacts of bleeding disorders
Debra Pollard	Clinical Nurse Specialist	Royal Free	Women
Kate Khair	Professor and Clinical Academic	GOSH	Paediatrics, Outcomes
Mike Laffan	Professor and Consultant	Imperial	Von Willebrand Disease
Mike Makris	Professor, Consultant, Centre Director	Sheffield	Assays, Platelet defects, Hep C, Adverse event reporting
Rezan Abdul-Kadir	Consultant Gynaecologist	Royal Free	Women, Obstetrics and Gynaecology
Lochana Nannayakkara	Dentist	London	Dentistry
Vacancy	Clinical Psychologist		
Musrat Pinnu	Social Worker	Leeds	Paediatric Social Work
Tom Burke	Health Economist	HCD Economics	
Susie Shapiro	Consultant	Oxford	Rarer Bleeding Disorders
Vacancy	Consultant		Gene Therapy
Vacancy	Consultant		Inhibitors
Vacancy	Paediatric Consultant		Paediatrics

Question 13: How and why was the Medical Advisory Panel established within the Society?

174. To understand how and why the Medical Advisory Panel was established, the Inquiry may wish to refer to the evidence given by former staff and Trustees of The Society. Set out below are a number of relevant extracts of evidence.

175. David Watters makes extensive comments about the Medical Advisory Panel at paragraphs 34 to 56 of his statement dated 18 January 2021 [WITN3429001]. In relation to its establishment, he states:

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

176. In his witness statement dated 9 April 2021, Peter Wetherell [WITN3912001] states the following about the purpose, function and responsibility of the Medical Advisory Panel:

> *[14] To the best of my knowledge the purpose, function and responsibility of the Medical Advisory Panel was to provide advice in relation to the clinical aspects of managing and treating haemophilia. I do not recall any change during my time on the Executive Committee. I was however shocked to since learn that the Medical Advisory Panel did not sit as a Panel and in fact it was a loose arrangement where no minutes of meetings were made.*

177. Simon Taylor gives the following evidence in his statement dated 22 April 2021 [WITN4500001]:

> *[59] I had no direct dealings with the Medical Advisory Panel (MAP) during my tenure that I can recall. As an Executive Committee member, we received feedback from the Chairman Rev Tanner, David Watters or Graham Barker, who were the primary points of contact with the MAP. Regarding its purpose, functions and responsibilities are concerned, the situation is set out in*

[HSOC0010470] in the report dated November 1991. Prior to this review, I understood the MAP to be a group of leading haemophilia clinicians that were consulted by the Society on an ad hoc basis. I believe that the review recommendations were implemented to put the MAP in a more formal basis.

178. Set out below are a number of documents which may assist the Inquiry's understanding of the Medical Advisory Panel's role in relation to The Society:

   a. A letter from David Watters to Dr C. A. Ludlam dated 8 August 1988 (Exhibit WITN6392159) which notes: *"The Medical Advisory Panel has, until now, not played a major part in the life of The Society. However, it is the clear wish of the Executive Committee that this situation should change. I could envisage no more than two, or at the very most three meetings during the course of any one year. We would normally try to link them in with the other Centre Directors meetings in London, or the London area. I think it is essential that the MAP be consulted on, for instance, treatment and blood products, especially since it is in everyone's interest that we should all "say the same thing". In addition a member of the Medical Advisory Panel review applications for research grants from time to time where the Council of the Society, or the Executive Committee, wish to have a more informed view of applications received"*
   b. Minutes and Agenda of Medical Advisory Panel Meeting on 9 April 1992 (Exhibit WITN6392160) note at point 92.05 that The Society had produced a hepatitis leaflet for its members and that a draft had been sent to several Centre Directors;
   c. Minutes of the meeting of the Medical Advisory Panel on 13 November 1992 (Exhibit WITN6392161) which note at point 92.29 that *"Members asked to send Society copies of relevant articles to ensure Society not dependant on views of those with vested interest"*
   d. A letter dated 29 March 1993 from Dr Mayne to David Watters includes suggestions for improvement of the Medical Advisory Panel (Exhibit WITN6392162);
   e. When necessary, the Medical Advisory Panel was asked to assist with specific topics. For example, in 1994, the Medical Advisory Panel produced a draft statement on Zidovudine (AZT) (see page 1 of the Notes of a Meeting of the Medical Advisory Panel held on 11 March 1994 (Exhibit WITN6392163);
   f. The Report, "Medical Advisory Panel: approval of new membership", by Karin Pappenheim, June 1999 sets out information about approval of new

membership to the Medical Advisory Panel and the role of the Medical Advisory Panel (Exhibit WITN6392164A).

Question 14: Who decided which clinicians would be members of the Panel? Why were the clinicians on the panel chosen to be members of it?

179. At paragraph 36, of his statement dated 18 January 2021 [WITN3429001] David Watters provides evidence about the selection of clinicians to be members of the Panel:

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

180. In his witness statement dated 9 April 2021, Peter Wetherell [WITN3912001] states the following about selection of clinicians to be members of the Medical Advisory Panel:

> *[16] I do not recall that the Haemophilia Society appointed members of the Medical Advisory Panel, or had any influence in the selection process. The membership of the Medical Advisory Panel was listed in the Annual Report each year and was thereby formally noted by the Council of the Haemophilia Society when adopting the report at the A.G.M.*

181. In her witness statement dated 14 May 2021, Karin Pappenheim [WITN4504001] comments on the selection criteria for membership to the Medical Advisory Panel as follows:

> *[91] Membership of the MAP did change over time, as it was to be reviewed annually after each AGM by the Society's CEO and Board, according to my report to the Board cited above [HSOC00023999]. The implementation of that annual review would be recorded in board minutes, which are held in the Society's archives. I believe that such a review of the membership would have been carried out as originally envisaged. Selection criteria, to my recollection, were not set out formally. Changes in the membership would have reflected the original intention to ensure a multi disciplinary spread of experts.*

182. 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) said in relation to the Medical Advisory Panel [WITN5428001]:

> *I only vaguely remember the Medical Advisory Panel but I do recall that haemophilia centre directors were involved with publications at times. For example, the Fact Sheets (Dr Charlie Hay assisted with Routes of Transmission, Dr Chris Ludlam and Dr John Hanley assisted with Liver Biopsies). I think there may have been some hepatologists on the Medical Advisory Panel as well as haemophilia specialists but I am not certain.*

183. Exhibit WITN6392164B sets out the membership of the Medical Advisory Panel in the 1980s. The composition of the panels throughout the years are also set out in The Society's Annual Reports. Set out below are a selection of documents which relate to appointments to the Medical Advisory Panel:

    a. Minutes of a meeting of the Council of The Haemophilia Society on 12 March 1967 (Exhibit WITN6392165) record on page 3 that it was agreed that a number of doctors be re-invited to continue as members of the Medical Panel and to ask them if they felt the Panel should be enlarged.
    b. Minutes of a meeting of the Council of The Haemophilia Society on 30 April 1967 (Exhibit WITN6392166) record at page 1 that it was decided that no

change be made to the doctors to be invited to form the Medical Panel (as noted in the Minute from 12 March 1967).

c. Minutes of a meeting of the Council of The Haemophilia Society on 28 April 1968 (Exhibit WITN6392167) record at page 2 the names of the people that would form the Medical Advisory Panel to The Society for the year 1968 to 1969.
d. Minutes of a meeting of the Council of The Haemophilia Society on 27 April 1969 (Exhibit WITN6392168) record at page 3 agreement to invitations for membership to the Medical Advisory Panel.
e. Minutes of the meeting of the Council of The Haemophilia Society on 26 April 1970 (Exhibit WITN6392169) record at page 2 discussion of suggestions for increasing the number of doctors on the Medical Panel *"but the Chairman thought that this should be viewed with great caution. The Panel as it existed was of immense use and value to the Society in many ways, and that increasing its size might tend to make it less effective. He thought the views of the Medical Panel itself would be important on this matter. Dr Dormandy was asked and agreed to contact members for their opinions.*
f. Minutes of the meeting of The Council of The Haemophilia Society on 4 July 1970 (Exhibit WITN6392170) address at page 1 the topic of increasing the number of members on the Panel.
g. Minutes of the meeting of The Council of The Haemophilia Society on 25 April 1971 (Exhibit WITN6392171) record at page 3 agreement to the formation of the Medical Panel for the ensuing year.
h. Minutes of the meeting of The Council of The Haemophilia Society on 30 April 1972 (Exhibit WITN6392172) record at page 3 that the Chairman said he *"felt that the Medical Panel was an important cornerstone to the Society"* and proposed the panel members be invited to continue as The Society Medical Advisory Panel for the ensuing year.
i. Minutes of the meeting of The Council of The Haemophilia Society on 27 April 1974 (Exhibit WITN6392173) record at page 2 that a medical advisor to the Scottish Group was appointed.
j. Minutes of the Annual General Meeting of The Haemophilia Society on 30 April 1977 (Exhibit WITN6392174) record at page 2 that there was consideration of adding two further members to the Medical Advisory Panel, if the existing members approved nominations.
k. Minutes of the Annual General Meeting of The Haemophilia Society on 26 April 1980 (Exhibit WITN6392175) record at page 2 that Professor Arthur Bloom and

Dr Peter Jones had accepted invitation to join the Medical Advisory Panel and that other members had been re-elected.

l. Minutes of the Annual General Meeting of The Haemophilia Society on 23 April 1983 (Exhibit WITN6392176) record at page 2 that a new Medical Advisory Panel had been re-elected.

m. Minutes of meeting of the Council of The Haemophilia Society held on 6 June 1992 (Exhibit WITN6392093) record at page 4 that the Council accepted the suggestion for a re-constituted Medical Advisory Panel.

n. Minutes of the Executive Committee on 4 February 1993 (Exhibit WITN6392177) notes that Dr Christine Lee would be appointed to the Medical Advisory Panel following the death of Professor Arthur Bloom.

o. Minutes of the meeting of the Council of The Haemophilia Council 27 February 1993 (Exhibit WITN6392178) record at page 5 that the Medical Advisory Panel was by this point was reduced in size.

p. Minutes of the meeting of the Executive Committee on 1 April 1995 (Exhibit WITN6392179) record that Dr Mayne resigned from the Medical Advisory Panel and it was agreed that Dr Paula Bolton Maggs would be invited to replace him.

184. Members of the Medical Advisory Panel were also appointed as members of The Society's committees. For example, Minutes of the meeting of the Council of The Haemophilia Society on 24 November 1991 (Exhibit WITN6392180) record at page 3 that Brian Colvin had accepted an invitation to join the Policy Committee; and that Mark Winter had joined the Members Services Committee.

Question 15: When was the panel expanded to include clinicians who were not haematologists? Why was that decision taken? Why was the need for non-haematologists to be members of the Panel not considered at an earlier point in time?

185. The reason why non-haematologists were not considered sooner is not clear from the documents that I have seen. However, there is no reason to believe that The Society had a closed mind to the involvement of disciplines outside haematology. The Society has a long history of drawing on advice from varied disciplines, including through publication of articles by authors from multidisciplinary backgrounds in The Bulletin. Set out below is a selection of examples:

a. The Bulletin No. 1 1979 (Exhibit WITN6392144) at page 6 under the heading "Your problems: Your letters answered by Vicki Stopford", which records a social worker (Vicki Stopford) providing advice to members;

b. The Bulletin No. 3 1995 (Exhibit WITN6392147) records at page 8 under the heading “Physiotherapy and muscle bleeds” an article by a Clinical Specialist Physiotherapist;

186. Set out below are a number of documents which may assist the Inquiry in relation to the professional backgrounds that panel members held.

187. Minutes of a meeting of the Executive Committee on 28 February 1991 (Exhibit WITN6392181) record at page 3 in relation to the Medical Advisory Panel that:

> *There was a general feeling that the Society did not get a great deal out of the present system, and that perhaps other ways of extracting more out of the Panel should be devised. The Chairman said that the Panel had been established at a less dynamic time in the Society's history, and that if its performance was perceived as disappointing the Society should take it upon itself to change matters. The Committee agreed to the appointing of a Project Team consisting of Mr Watters, Mr Milne and Mr Cowe, serviced by Mr Barker, which would look at ways of accomplishing an overhaul. The Team could co-opt other people, and should consider including members of the Panel in its deliberations. Mr Watters suggested that the new improved Panel should take into account scientific as well as medical matters.*

188. Minutes of the meeting of the Member Services Committee dated 18 May 1991 (Exhibit WITN6392182) record agreement about the structure of the Medical Advisory Panel:

> *There was a discussion of a paper by Mr Barker, previously circulated, on the findings of a Project Team set up to review the workings of the Medical Advisory Panel. It was generally agreed that the function of MAP needed to be redefined, but that its structure should not necessarily be changed as radically as had been suggested. For instance, it was felt that the inclusion of nurses, social workers and physiotherapists was unnecessary and would prove to be unworkable in practice. The Committee agreed the following points:*
>
> *i) MAP should continue to exist.*
> *ii) MAP should not contain non-medical members.*
> *iii) Members should have specific areas of interest.*

> *iv) The Panel should serve a broader function, including education and conferences. Members could be asked to give a seminar on hepatitis, for example, or organize a conference on a specific subject.*
>
> *v) A document detailing how MAP should be run might be a more suitable way of structuring the Panel's activities than individual job descriptions or contracts for members.*
>
> *vi) The AGM should be asked to give responsibility for appointment of medical advisers to the Executive Committee.*
>
> *vii) The Society would hold the right to co—opt any new members it wished.*
>
> *viii) Consultation on other health care issues would not be required by the constitution.*

> *These views would be presented to the Project Team for further discussion before submission to the Executive Committee on 6 June 1991.*

189. Minutes of a meeting of the Executive Committee on 6 June 1991 (Exhibit WITN6392183) record at page 3 that there was discussion of additional disciplines to the Medical Advisory Panel:

> *Medical Advisory Panel: Mr Milne reported that a Project Team consisting of himself, Mr Cowe and Mr Barker had met to discuss the future of MAP and Mr Barker had summarized the findings in a paper, which had been presented to both the Policy and Member Services Committees. Both Committees had felt that it was useful to have this regular forum, the Society being constitutionally obliged to have a MAP. However, there had been disagreement on whether the structure of the Panel should be broadened to include, for example, social workers, nurses and physiotherapists, or whether it should remain composed only of doctors. It was apparent, also, that the Society needed to define the function of the Panel, and to make clear what it expected of the Panel. For instance, members might be requested to speak on specific topics at seminars, or provide papers for Society publications. After some discussion the Committee agreed that Mr Watters would approach Dr E Mayne and other members of the MAP for their opinions on the matter. The Project Team was thanked for its work, and disbanded.*

190. Minutes of the Executive Committee of The Haemophilia Society meeting, 4-5 October 1991 (Exhibit WITN6392061) record at page 3 that the re-constituted 1992 Medical Advisory Panel should comprise of five members: the Chairman and Vice Chairman of the Centre Director's Organization, the Chairman of the Hepatitis Working Party, the Chairman of the Centre Directors' Adverse Reactions Working Party and one other Centre Director. The Chairman voiced a wish to meet with the Project Team (Mr Cowe, Mr Milne and Mr Barker) and suggested that a report be written and circulated for comment before presentation at the Chairman's Conference. This was agreed.

191. Minutes of the Executive Committee on 14 November 1991 (Exhibit WITN6392155) record at page 2 that the new re-organised Medical Advisory Panel would have *"a set of proper terms of reference".*

192. Minutes of the meeting of the Council of The Haemophilia Society on 24 November 1991 (Exhibit WITN6392180) record at page 2 discussion about restructuring the Medical Advisory Panel, noting that: *"The Executive Committee had appointed a Project Team to review the Panel's roles and responsibilities. It has been felt, said Mr Watters, that the Panel was too big and unwieldy and that it did not always produce entirely satisfactory results. The Panel had no terms of reference from which to work and members seemed, at times, unable to re-adjust to their appointed roles as advisors to the Society…"*

193. Notes of a meeting of the Medical Advisory Panel held on 11 March 1994 (Exhibit WITN6392163) record at point 5 that in the context of discussing Hepatitis C Professor Christine Lee suggested she *"felt it would be helpful if there could be a joint educational meeting for haemophilia consultants and liver doctors".*

194. Minutes of a meeting of Executive Committee on 16 May 1992 (Exhibit WITN6392092) record at page 4 that *"it was agreed that gene therapy should be amongst the Panel's consideration, and therefore Dr Tuddenham should be asked to become a member"*

195. Minutes of Health Sub-Committee Meeting held on 7 September 2005 (Exhibit WITN6392184) note under the heading "Discuss future of health sub-committee and Medical Advisory Panel" that is was agreed to recruit two paediatricians and to invite a dentist to the panel.

Question 16: Did the Society ever question or challenge information provided to them by a clinician? What reliance did the Society place on the Medical Advisory Panel and the provision of medical information by them?

196. As mentioned above, 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. The Medical Advisory Panel were also responsible for dealing with grant applications for research projects. Set out below are a selection of documents and evidence which illustrates The Society's relationship with the Medical Advisory Panel.

197. Minutes of a meeting of the Council of The Haemophilia Society on 24 October 1970 (Exhibit WITN6392124) record that in the course of discussion about The Society sponsoring a conference about treatment of haemophilia, the Medical Advisory Panel (along with haematologists, Directors of Haemophilia Centres and others) should be invited; and that steps should be taken to approach the Medical Panel to find out "any dates of likely gatherings of haematologists in the near future in England so that the Conferences could possibly link up":

> *In view of the widely differing standards and methods of treatment for haemophiliacs throughout the country it was suggested that a One-Day Conference might be sponsored by the Haemophilia Society to which as many as possible of people connected with the treatment and welfare of haemophiliacs should be invited, e.g. The Medical Panel, Haematologists, Directors of Haemophilia Centres, etc. All members of the Council agreed that this was an excellent idea and it was decided that the first steps to be taken were to approach the Medical Panel and to find out the dates of any likely gatherings of Haematologists in the near future in England so that the Conference could possibly link up.*

198. There is a memo from Graham Barker to the Hepatitis Project Team dated 30 October 1991 regarding comments from several doctors (Exhibit WITN6392185). This provides an example of how The Society sought the opinions of clinicians in order to assist with its work.

199. In his witness statement dated 9 April 2021, Peter Wetherell [WITN3912001] states that he believes that the *"judgement of the Executive Committee was informed by the advice of the* Medical *Advisory Panel at all times."* Similarly, David Watters comments at paragraph 52 of his statement dated 18 January 2021 [WITN3429001]:

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

200. Simon Taylor also gave similar evidence in his witness statement dated 22 April 2021 [WITN4500001]:

> *[60] None of the members of the Executive Committee or any members of staff were clinicians or scientists expert in haemophilia. Accordingly, we were highly reliant on the MAP for such opinions. Other sources were the general media, information shared from other organisations such as the World Federation of Haemophilia (WFH) or the British Liver Trust, and informal conversations with Haemophilia clinicians who did not happen to sit on the MAP.*
>
> *[61] The Society did not have the expertise or resources to conduct its own scientific research or to review of scientific journals and papers. The MAP consisted of clinicians who were national, and in some cases world, experts in all aspects of haemophilia care. It is my understanding that the nature of haemophilia as a condition made it a complex interaction with other conditions such as hepatitis and orthopaedics, and thus a pure specialist in another discipline might not have the experience or expertise to advise on its presentation in haemophilia. Accordingly the MAP as experts in haemophilia were the most appropriate expert advisors that the Society could call on for advice.*

201. In his statement dated 22 April 2021 [WITN4500001], Simon Taylor also gives evidence about the context in which The Society relied on advice from the Medical Advisory Panel:

> *[335] I would like to bring to the Inquiry's attention a range of matters that provide a deeper context to how the Haemophilia Society acted over the period I was involved with its work.*
>
> *[336] The Society was always a very small charity, with limited income and resources. It was not until the appointment of David Watters in about 1980, that the Society had any full time staff.*
>
> *[337] The level of funding was severely limited, and was mostly in the form of community fundraising, such as raffles, indeed I believe that for a time the Christmas Raffle was the largest single source of income, local events, individual fundraising efforts etc. This changed somewhat as the impact of the HIV epidemic amongst the haemophilia community grew and government grants, grants from charitable trusts and commercial donations became available.*
>
> *[338] At no time was the Society in a position to pay for its own scientific and medical expertise, and so at all times it had to take on trust, the advice given to it by clinicians and scientists within the haemophilia community. The Trustees were all lay individuals in this connection.*
>
> *[339] The Society had to make policy, and take decisions, based on the medical and scientific advice available to it as a group of lay individuals. As is frequently the case with emerging threats, this advice was frequently confusing, conflicting, incomplete and with hindsight, some of it was incorrect.*

202. I 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.*

203. However, there is evidence that The Society did not always follow advice given by the Medical Advisory Panel. Minutes of a meeting of the Executive Committee held on 29 July 1993 (Exhibit WITN6392096) record at page 6 under the heading "High Purity Blood Products" record as follows:

> *Mr Barker reported that the Centre Directors Regional Committee had recommended that HIV positive patients should receive high purity blood products but had made no distinction between monoclonal products and those produced by ion exchange chromatography. There was increasing evidence that it was only the monoclonal products that had a beneficial impact on patients' CD4 cells. In England the new Alpha product was made from an ion exchange process and was cheaper than the monoclonal products. In Scotland and Northern Ireland the main product available was produced from an ion exchange process.*
>
> *The issue had been discussed at the meeting of Committee B on 15 July 1993 The Committee had felt that the evidence of beneficial effects on the CD4 counts of HIV positive patients with haemophilia should be offered monoclonal products was very strong, but that there was no similar evidence for ion exchange products. Therefore, the Committee recommended that The Society's policy should be that all HIV positive patients with haemophilia should be offered monoclonal products and that this policy should be actively promoted, even if it did not have the full backing of the Medical Advisory Panel.*
>
> *There was a brief discussion and the Committee endorses Committee B's recommendation. It was further agreed that the decision be presented to MAP and the Panel's advice sought.*

Question 17: What was the purpose of the Society's attendance at the UKHCDO meetings? Was the Society invited to join any working party of the UKHCDO? If so, what was the Society's role on such a working party?

204. Minutes of the meeting of Council of The Haemophilia Society on 25 November 1972 (Exhibit WITN6392186) record under the heading "Other business" at page 4 that *"At Dr Kuttner's suggestion the Council agreed that a request be made to Dr Biggs for the Society to be allowed to send one or two observers to any future Centre Directors' meetings."* I understand that this is the first documented reference of The Society seeking to attend UKHDCO meetings.

205. Minutes of the meeting of Council of The Haemophilia Society on 17 March 1973 (Exhibit WITN6392187) record the response from the Medical Advisory Panel to The Society's request at page 2:

> *A letter had been received from Dr. Biggs saying that in her own view the work of the Haemophilia Society and that of the Centre Directors covered such different aspects of the problems of haemophiliacs that they were best kept separate. If the Council still felt they wished an observer to be present at the next meeting of Directors then the request should be sent to the Chairman Professor Blackburn. It was agreed that the Secretary should write to Professor Blackburn.*

206. No historical documents have been identified which respond to this question. However, some of the reasons as to why The Society attends UKHCDO meetings today include: to understand the current issues and thought processes of the UKHCDO; how the centres operate; and what is on their agendas.

207. 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.*

208. 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.*
>
> *[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.*

Section 4: Relationship with pharmaceutical companies

Question 18: How was the work of the Society funded generally? What proportion of the Society's work was funded by pharmaceutical companies? Please set out the funding received from pharmaceutical companies over the years 1970 to 2000.

209. In his statement dated 22 April 2021 [WITN4500001], Simon Taylor provides the following evidence about the extent of The Society's reliance on financial contributions from pharmaceutical companies manufacturing and/or supplying blood products:

[116] Funding from pharmaceutical companies of patient groups was common at the time across a wide range of health conditions, many health based charities received funding of this kind. More recently restrictions have been placed on such funding by the Association of the British Pharmaceutical Industry (ABPI), but during the 1980s and 1990s this was considered normal practice.

[117] My view of the blood product companies, which I believe was shared by the Society generally, was one of wary cynicism. We were only too aware that it had been largely their products, and their plasma collection practices, that had caused the infected blood epidemic amongst the haemophilia community. As a consequence, we did not trust them, however we felt little compunction in seeking money from them to help respond to the problems that they had in large caused.

[118] Before the HIV epidemic the Society's main sources of income was community fundraising including: the Christmas raffle; an annual Ball; fundraising by local groups; individual fundraising by members etc. As the scale of impact on the Society's work in supporting the community grew, a considerable amount of money was received from the Government in the form of 'Section 64' grants. In addition, a number of pharmaceutical companies provided, on request, contributions to activities and events, however I do not believe that the total of pharmaceutical company contributions ever became a significant proportion of the Society's funding.

[119] The normal procedure as I recall, was that the Society would decide to hold an event, such as a members' conference or an information day, and then approach the pharmaceutical companies to see if they would make a contribution to the cost. I do not recall any examples of the companies approaching the Society with a request to undertake any activity in return for financial support.

[120] I do not recall in detail all activities that companies gave contributions to, they were in main member events as outlined above or participation in WFH or EHC meetings. A number of companies made financial contributions to publications such as The Bulletin.

210. Funding received from pharmaceutical companies is also recorded in Minutes of Executive Committee meetings, which the Inquiry has access to. Set out below are a selection of documents which record discussion about funding received from pharmaceutical companies. Some entries below also note caution with respect to this funding and any associated perceived on actual influence on The Society:

a. Minutes of the Executive Committee meeting on 4 February 1993 (Exhibit WITN6392177) at page 4 record discussion about funding from BPL and Proton Products.
b. Minutes of the Executive Committee meeting on 25 March 1993 (Exhibit WITN6392154) at page 5 record The Society's position regarding assigned sponsorship by Armour Pharmaceuticals, BPL, Porton Products and Octapharma. There is also potential funding indicated to be available from Alpha UK and Immuno. This minute also records that funding had been received from an international federation of plasma producers, noting that, *"The Committee established that the group of plasma producers was a trade consortium with vested interests. It was felt that caution should be exercised in the way the Society accepted and made use of funds from commercial sources, while accepting Mr Taylor's point that the Society would not have been able to be influential in Europe had it not received sponsorship. Mr Clarke proposed that, when taking Sponsorship, the Society adjust its budget accordingly and that the Executive Committee should approve expenditure beforehand. This was noted."*
c. Minutes of a meeting of the Executive Committee held on 29 July 1993 (Exhibit WITN6392096) record at page 7 that David Watters was in discussions with a number of pharmaceutical companies concerning sponsorship in 1994: *"Among the emerging proposals was a specific one from Cutter—Miles (Bayer) to fund a national conference for people with haemophilia, Centre Directors, nurses, social workers, physiotherapists, in fact the entire health care team. The talk had been in terms of £15,000 plus. It was hoped that other pharmaceutical companies would pay for satellite sessions relevant to their own activities. Any direct promoting of products would not be permissible…"*
d. Minutes of an Executive Committee meeting on 7 May 1994 (Exhibit WITN6392062) record reports about discussions for potential funding from Alpha Pharmaceutical and Proton for sponsoring sessions at the Chairman's Conference.

e. The June 1995 edition of The Bulletin (Exhibit WITN6392189) notes at page 12 that the pharmaceutical industry had contributed towards the cost of the year's Adventure & Sport holidays for young people with haemophilia. Alpha Therapeutic, Bayer, BPL, Immuno and Pharmacia had all pledged support.

f. The September 1996 edition of The Bulletin (Exhibit WITN6392190) notes at page 2 that publication of the edition was funded by BPL.

g. Minutes of the Board of Trustees meeting on 13 February 1997 (Exhibit WITN6392191) note that: *"Discussions arose regarding the possible influence on the Bulletin by pharmaceutical companies. The Chairman called for a vote on a proposal by Mrs Norm a Guy, to decide whether the Bulletin was to be a future budgeted item. The final decision, was that the Bulletin would continue to be produced even if sponsorship was not forthcoming. However, companies who help fund the Bulletin via the "Pharmaceutical Industry Fund" will be thanked in each issue. This was seconded by Mr Gordon Clarke and unanimously accepted."*

h. The Chief Executive's Report dated 21 March 1997 (Exhibit WITN6392192) sets out monetary support for the Pharmaceutical Industry Fund from BPL; Bayer; Baxter; Centeon; Alpha and Genetics Inst.

i. The 1997 (No. 1) edition of The Bulletin (Exhibit WITN6392193) acknowledges at page 2 the financial support received from companies *"whose contributions to [The Society's] Pharmaceutical Industry Fund help [The Society] to provide [its] membership services: Alpha Therapeutic; Bayer; Baxter Healthcare; BPL; Centeon; and Genetics Interest Group."*

j. An invitation to a local group meeting on the topic of "Orthopaedic problems in haemophilia" on 23 September 1997 (Exhibit WITN6392194) notes that the event was sponsored by Alpha Therapeutic.

k. The Chief Executive's Operational Report from the Board of Trustees meeting on 25 September 1998 (Exhibit WITN6392195) record that funding from Bayer was used the upgrade The Society's computer systems.

211. The Society has prepared a document which sets out in as much detail as possible based on the information available funding received by The Society from pharmaceutical companies from 1970 to 2000. The figures in this spreadsheet have been drawn from The Society's Annual Reports, Financial accounts, Bulletins and Minutes of Meetings. I am aware that The Society's employees have done their best to prepare an accurate record; but acknowledge that there are gaps. I understand the gaps in the records relate to the way that financial records have been recorded has

changed over time; and The Society does not have full financial records dating back to the 70s.The spreadsheet can be found at Exhibit WITN6392196).

212. 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. As stated above, 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.

213. 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.

214. 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.

215. 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.

216. 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.

217. 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.

218. It is my understanding that the EHC also receives donations from pharmaceutical companies. The EHC's 2002 Annual Report (Exhibit WITN6392197) 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.

219. 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.

Question 19: Why did pharmaceutical companies attend events run by the Society?

220. I have not seen any documents which assist in responding to this question on a historical basis. The evidence to the Inquiry from Mr Christopher Bishop may assist.

221. Currently, the reason pharmaceutical companies are invited to attend events is because they often produce patient facing material, which is useful. Patients like the opportunity to meet with company representatives and see for themselves what the

company has to offer, any new advances, how these might be of benefit and to ask questions or provide feedback. The Society feels it is important that the companies understand the needs of the community and get information from the horse's mouth. For example, when they are producing training material on products (which they have to do); it is good for them to understand what sort of material works and is easily understood, and what goes over people's heads or does not address the topics they want addressed, or is otherwise unhelpful.

222. I note that pharmaceutical companies do not attend all of The Society's events. At times, they are excluded for the purpose of member privacy. More generally, they have no say over the content of sessions; and they always attend as observers.

Question 20: Please consider RFLT0000056. Please explain why the Society was involved in producing the Armourpage News.

223. Exhibit WITN6392198 is an edition of The Bulletin (1991) No. 2 which contains news about Armourpage users.

224. In the 1990 (No. 2) edition of The Bulletin (Exhibit WITN6392199) at page 7 here is an explanation of the background about the Armourpage service:

> *A new free paging service linking schools and parents at the touch of buttons enabling children living with haemophilia to get treatment much quicker and offering parents a little more freedom had been launched in a joint venture between Armour Pharmaceuticals and British Telecom.*
>
> *They've called the small gadget Armourpage. Parents of children with haemophilia hold a simple BT tone pager while the school has a 10-digit telephone number which they simply dial to set off the "bleep" on the pager.*
>
> *As long as the parents are within the specified region the will be contacted within minutes of any crisis.*
>
> *The Society has co-operated in the trials through the* GRO-A *family in Liverpool, the* GRO-A *from* GRO-A *and* GRO-A *in* GRO-A *and a quote from Mrs* GRO-A *probably sums up the value of this new idea: "Armourpage has improved the quality of our lives no end, who would think a little black box could do so much."*

> *Society Chairman, the Revd Alan Tanner, in welcoming Armourpage said that "this new initiative is not only an efficient way of ensuring that children with haemophilia get treated quickly, but also provides the parents or guardian with greater freedom".*

225. On the same page, there is a note which states that Armour Pharmaceutical helped to fund The Bulletin that year and there is a photograph of Chris Bishop handing over a cheque for £10,000 to David Watters. Minutes of a meeting of the Council of The Society on 17 March 1990 (Exhibit WITN6392082) record at page 4 a discussion about the influence of sponsoring bodies on The Society's policies:

> *… in connection with The Bulletin Mr Cowe drew attention to the fact that the Armour Pharmaceutical Company was now sponsoring this publication for the remainder of this year. This had been made possible through a single grant of £10,000. One member voiced concern that the Society should be seen to use money from Armour Pharmaceutical Company since they could be seen as one of those who introduced HIV to the UK. This view was not accepted by the meeting and it was felt to be important that the Society used any opportunity to further its work providing that the sponsoring body could not, in any way, influence, or be seen to influence, the policy and direction of the Society.*

226. The Society's third edition of The Bulletin for 1990 (Exhibit WITN6392200), sets out a positive review from an Armourpage user at page 6. It states:

> *My husband and I would like to thank the Society for setting up the 'Armourpage'. Our grateful thanks go to Armour Pharmaceuticals and British Telecom for sponsoring such a worthwhile service. We are now into the third week of using the pager, and I can't tell you how reassuring it is to know that within a matter of minutes we can be contacted if need be. Our son, is now 21 months old and you can guess — into everything. We feel so much more confident when we have time out together, and family* GRO-A *are certainly a lot happier to look after him for longer periods. Thank you again, and for your support through the 'Bulletin' and Update. Yours sincerely [REDACTED]*
>
> *Editor: We are receiving a large number of letters expressing these sentiments.*

227. The Society's General Secretary's Report to the Executive Committee dated 10 May 1990 (Exhibit WITN6392201) explains that the "Armourpage Scheme" launched in April of the same year. It states at page 3:

> *GS90.08 ARMOURPAGE: The details of ARMOUPAGE took up a fair amount of time during the period leading up to the launch on April 26. Our computer 'knew' 725 parents of children with haemophilia aged 16 or under and, as at the day of the launch, some 450 had applied for pagers under the Armour scheme. It is likely that payment of rental charges will continue well beyond the first year. Armour are also meeting the total account for paper, postage and copying costs, plus staff time incurred.*

228. The February 1992 edition of The Bulletin (Exhibit WITN6392202) notes in an article at page 8 titled "*The Armourpage survey results: A look at how useful it is*" that in April 1990, The Haemophilia Society, Armour Pharmaceutical Company Ltd and British Telecom offered a free paging service called "Armourpage" to all parents/guardians of children with haemophilia (under the age of 16). It provides survey results and recounts positive experiences that users have had with the service.

229. The Minutes of the Member Services Committee dated 23 January 1993 (Exhibit WITN6392203) record discussion about the running costs of Armourpagers:

> *Mr Watters raised the issue of Armour's sponsorship of Armourpagers, a sum of £38,000 a year. He had recently discussed ways of reducing this cost with the company: the setting—up costs were high, and the subsequent running costs were relatively low. Several pagers (£65 each) had been lost by their owners. Mr Watters suggested to the Committee that a way of keeping down expenses would be for people to pay their own quarterly hiring bills. The Committee agreed.*

230. I have also seen an undated document titled "Armourpage Case Study Information Sheet" addressed to "Dear Member" (Exhibit WITN6392204). This document appears to have been prepared by a public affairs agency (although I cannot be certain of this) and it is asking for case studies from users to gain press interest:

> *Dear Member*

As a user of "Armourpage" you already know the reassurance and additional freedom it can bring. You can also have a detailed knowledge of haemophilia and first hand experience of the implications it can have on your family.

Armourpage has helped hundreds of children with haemophilia – and their families – to lead a more active life since its introduction two years ago. The Haemophilia Society also continued to ensure that people with haemophilia and their families receive adequate care and that their wellbeing is not threatened or jeopardised in any way.

Increasing the Level of Awareness of Haemophilia

Armour Pharmaceuticals Co. Ltd, which donates Armourpages, BT which supplies the paging service and The Haemophilia Society are all committed to raising the level of awareness and understanding of haemophilia in order that the Haemophilia Society can continue to increase the support it offers to the haemophilia community. One way of increasing awareness is through effective "press relations". Over the next few months we will be encouraging local newspapers across the country to take an interest in the problems and triumphs of people with haemophilia and their families. To do this we need your help.

Why is "Press Relations" important to me?

Unfortunately many people are still unaware, even ignorant, about the facts of haemophilia. For people with haemophilia and their families this is where many of the problems of living with the disorder begin. Effective press relations on a local level can help to raise the level of understanding and awareness among the general public.

Common Misconceptions

- *Many people still think that you can catch haemophilia from somebody who has it - just by standing close or sharing cutlery.*
- *There is still a strong association between haemophilia, HIV and hepatitis due to the contamination of blood products in the early 80's. Coupled with general ignorance about HIV, discrimination against people with haemophilia - whether they have HIV or not - is still widespread.*

- *One of the sad things about HIV is that people have stopped telling others about their haemophilia so producing an added air of mystery surrounding the condition.*
- *Many schools and social organisations are not prepared to take responsibility for a child with haemophilia. This can present enormous restrictions for all the family.*

231. Another undated Society document (Exhibit WITN6392205) explains that the sharing of news about Armourpgae users was intended to raise awareness about haemophilia. I do not know who prepared this document. The document states:

> *The majority of people with haemophilia continue to lead active, near normal lives, playing many of the same sports, achieving academic excellence, building successful careers - and making the same mistakes as everyone else.*
>
> *Armourpage has helped many children to participate fully at school and has given parents added peace of mind and freedom.*
>
> ***How Can You Help to Increase Awareness and Understanding?***
>
> *By telling your story to your local newspaper you can:-*
> - *Explain the difficulties of life with haemophilia.*
> - *Talk about specific problems or discrimination you may have encountered.*
> - *Demonstrate how your family manages to lead a normal life with the help of The Haemophilia Society and other services like Armourpage.*
>
> ***Can Telling My Story Really Help to Change Attitudes in General?***
>
> *No single person can change the world's view of haemophilia overnight. But if we tackle the issue of raising awareness at a local level, eventually, your voice will strengthen the overall voice of the haemophilia community and that of the Haemophilia Society.*
>
> ***What do I do next?***

> *If you would like to become the subject of a case study please fill in the form below or telephone Sam Brown or Helen Plumtree at Sinclair Mason on* GRO-C GRO-C *Sam works on behalf of BT and will be coordinating the press relations activity for the Haemophilia Society and Armourpage.*
>
> ***How Will My Story be Handled?***
>
> *The first step is an informal chat about your child and your family.*
>
> *We will then approach local newspapers in your area to find out if they would be interested in running a story about you. At this stage we will not release your name – just a broad outline of your case.*
>
> *If there is sufficient from your local newspaper we will then write a story about you based on what you have told us. We will not include any information that you do not want us to, although it is essential that you give your real names.*
>
> *You will then have an opportunity to see the story and change any aspects you're not happy about before it is sent to the newspaper.*
>
> *We will also keep the Haemophilia Society informed at all times and we will send them a copy of your story in case they need to suggest any additions or changes.*

Question 21: Please consider HCDO0000276_047. Please explain why the Society was involved in producing the Alpha Therapeutic UK Ltd anniversary news.

232. At paragraph 75 of his statement, Andy Cowe states [WITN3647001]:

> *[75] In general, I am not aware of any pharmaceutical company representatives playing any active role in the content or presentation of our publications. They sponsored the publication but did not influence its content. The only article that might be an exception to that general rule is the Update dated April 1989 (document HCD00000276_018). This featured Alpha Therapeutic UK Ltd under the headline "ALPHA a decade of service to haemophilia". I have no knowledge of how it came to be featured, but it is reasonable to presume that it was initiated by the company.*

233. I have not seen any additional documents which might assist with providing a response to this question.

Question 22: What did the Society understand to be the benefit to the pharmaceutical companies of funding the work of the Society?

234. I have not seen any documents which answer this question definitively. I can surmise that it may have been for altruistic reasons; understanding customers better, which would lead to producing better materials; or understanding needs of community and to enhancing their reputation.

235. The earliest documentary evidence that I have seen of The Society seeking funding from pharmaceutical companies was in 1975 by way of a direct appeal that was sent to over 1,000 companies. This is recorded on page 2 of the minutes of The Society's Executive Committee on 13 November 1975 (Exhibit WITN6392206). Also noted in Executive Committee minutes from the same year (from a meeting held on 11 December 1975) is that *"a letter has been received from Serological Products Ltd expressing interest in supporting various research projects we had put to them".* (Exhibit WITN6392207A).

236. The September 1989 General Secretary's Report (Exhibit WITN6392207B suggests that Armour hoped that The Society might have a (small) role to play in facilitating discussions that might lead to image rehabilitation so that it could market Monoclate in the UK. Ken Milne's report of the September 1992 UKHCDO meeting records that Armour was "very interested" in The Society's proposed study with Professor Maynard at York University on health economics and evidencing the benefit of treatment changes and cost/benefit analysis generally (Exhibit WITN6392208).

237. I have set out below evidence previously given to the Inquiry by former Society staff.

238. In his statement dated 22 April 2021 [WITN4500001], Simon Taylor responds to a question about the motivations or expectations, if any, of pharmaceutical companies who donated to the Haemophilia Society; and whether there was an expectation that the Haemophilia Society would provide anything in return. He states:

> *[131] I believe guilt might have had a lot to do with it. I have no knowledge of any specific motivations and expectations by any of the companies. I expect*

> *they believed that by supporting some of the Society's activities, they might ward off criticism of their past actions, but that is speculation on my part.*
>
> *[132] I do not believe that there was any expectation that the Society would provide anything in return.*

239. In his statement dated 18 February 2021 [WITN3429001], David Watters states in response to the same question that was posed to Simon Taylor, as stated above:

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

Question 23: Other than the financial benefit, were there any other benefits to the Society of their links with pharmaceutical companies?

240. I believe that having links with pharmaceutical companies has benefitted The Society through:

   a. Understanding what assets companies had in development
   b. Having a direct line of communication with companies; meaning that The Society could inform the community about any product issues (for example, if there were a problem or batch withdrawal or issue that arose from products)
   c. Having an input into development of assets and materials for patients; if companies were looking to develop patient materials, The Society's involvement could give a better patient perspective
   d. Having an input into what would improve the quality of products - the Armourpagers project is a good example of The Society working together with a pharmaceutical company and this working well.

241. In his statement dated 22 April 2021 [WITN4500001], Simon Taylor states:

> *[126] There were two primary benefits of having a relationship with both BPL and the pharmaceutical companies. One benefit was the ability to gain an understanding of their products and processes, which was valuable as the Society sought to build its own knowledge and understanding of product safety and innovations. The other was financial, as outlined above, in that they were*

able to make contributions to events for our members that might not otherwise have been possible.

242. Minutes of the Executive Committee meeting on 7 July 1994 (Exhibit WITN6392209) record that Bayer had launched their recombinant Factor VIII product Kogenate; that The Society attended the launch meeting but did not attend the press conference, although Keith Colthorpe attended as an individual who was using the product. The same document notes that the European Haemophilia Conference would be held in London in October 1995; that a draft programme had been prepared for discussion with the Danish Haemophilia Society; and that funding would be sought from pharmaceutical companies.

243. Examples of The Society's members receiving benefits from pharmaceutical companies are set out below:

a. In March 1986, Mr Bishop attended The Society's Annual Conference and a patient of Professor Savidge's spoke to him about sero-converting on Armour product (Exhibit WITN6392210). That meeting could and should have benefitted the member but appears not to have done because, as he explained to the Inquiry, Mr Bishop appeared not to accept the significance of what he was being told.
b. In 1987, Mr Bishop was invited to come and explain Armour's new product Monoclate and the meeting took place in February 1988. Having access to the industry allowed trustees with haemophilia to ask questions of interest to members directly of pharmaceutical companies. (Exhibit WITN6392211) and (Exhibit WITN6392212).
c. Minutes of an Executive Committee meeting on 9 February 1995 (Exhibit WITN6392213) record that a writer employed by Bayer had been preparing an information binder for parents of newly diagnosed children.
d. Minutes of the Board of Trustees weekend meeting on 20-21 September 1996 (Exhibit WITN6392214) note that Bayer had agreed to produce 10,000 copies of "Haemophilia and the School".

Question 24: Did any pharmaceutical companies try to influence The Society in relation to:

a. The information provided to members about which blood products to use and/or their safety;

b. **Submissions the Society should be making to the Government;**
c. **Whether or not the Society should take a particular course in relation to any of the campaigns they pursued.**

244. I have seen no evidence of pharmaceutical companies trying to influence The Society in relation to any of the matters listed in this question. Certainly since I started my role at The Society there have been no such attempts.

245. In his statement dated 18 February 2021 [WITN3429001], David Watters states:

> *[196] Financial contributions were invaluable to The Society in meeting its income objectives. There was an even-handed application process made to each of those companies and to a huge number of charitable trusts. Every year applications would be made to these organisations and an equal opportunity was provided to all to respond as they felt fit, there were certainly no benefits deriving from it. Any funding received would be acknowledged within publications. As a charity we were under an obligation to do everything we could to fund the work and not refuse any donations. We were also required, as a charity, to publish the names of those who supported the work.*
>
> *[197] As stated in the letter provided by Thompsons to the Penrose Inquiry, dated 9 November 2011 [WITN3429029/PRSE0003528] The Society's approach to funding changed considerably during the 1980s and, as The Society employed more staff, its ability to raise more funds increased, which resulted in the pharmaceutical companies also increasing their donations. The letter also explains that "any donation made would have no influence over the conduct of the Society, its attitudes or its communications with its membership. The pharmaceutical companies who were prepared to donate sums to the Society were prepared to do so not in return for promotion of their products" [WITN3429029/PRSE0003528, page 2].*

246. 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) said in relation to the extent to which representatives of pharmaceutical companies assist I proposing and/or editing and/or selecting material for the Society's publications:

> *[35] I recall that pharmaceutical firms supported the Haemophilia Society's work financially, but from memory, firms had no input in terms of proposing and/or editing and/or selecting any material for the publications with which I was involved.*

247. Documents that I have seen demonstrate that The Society was careful to ensure that no product or company were favoured in The Bulletin. For example, in Minutes of the Executive Committee of The Haemophilia Society meeting, 4-5 October 1991 at page 7 (Exhibit WITN6392061):

> *28.6 The Bulletin 1991 Issue No 3: Mr Watters reported on a controversy that had arisen over the publication of three articles on monoclonal or high purity products in the recent issue of The Bulletin. Having read them, a few Society members had approached their Centre Directors with requests for the products and this had caused a certain amount of consternation to a few Directors. Dr Elizabeth Mayne had agree d to write an article for the next issue on some of the problems related to the use of high purity products, there by presenting the other side of the argument. The Chairman remarked that the Society might be perceived in certain quarters to be favouring a particular pharmaceutical company, and that such sensitivities ought to be borne in mind in the future. Mr Cowe said that The Bulletin was a forum for debate and should take into account all the medical evidence on a range of issues.*

Section 5: Relationship with Government

Question 25: Who were the key contacts that the Society have had in Government since 1970? Please describe how meetings were arranged, how it was decided who should attend from the Society and who within the Society determined the priorities for such meetings.

248. Over the years, The Society has lobbied and engaged with countless ministers and government officials.

249. To respond to this question, I have also set out relevant evidence given by Society Trustees and staff; and I have set out a number of documents which may assist the

Inquiry with gaining a snapshot of The Society's relationship with government. I hope that these documents assist in sufficiently responding the Inquiry's question.

250. In his statement dated 18 February 2021 [WITN3429001], David Watters describes the extent of his role and involvement with regard to the Society's interactions with and representations to the government:

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

251. David Watters states in relation to The Society's main points of contact in government and how meetings were arranged:

> *[137] At civil service level, Roger Moore was my main contact. In relation to how those relationships were formed, the key people had generally contacted The Society and we kept the relationship going on a regular basis. The Society would regularly write to civil servants and would try to follow up thereafter with meetings. We would always encourage members to write to their local MPs. The Society did not have a local MP as such. Therefore, MPs would only be able to be contacted by members of their constituency. The work of members lobbying their MPs would go on in the background and if we were coming up to a time when a campaign was about to be launched, I would, for instance, let a civil servant know that we were about to embark on that course of action, which would inevitably result in a meeting with a minister. In the meantime, however, the media was on the go, the Sunday Times in particular was carrying authoritative information from The Society.*
>
> *[138] Meetings with the Government were not regularly scheduled however, it was on a needs basis that we used to meet. Our offices were very close, because for much of the time The Society was based in Trinity Street, SE1 very near to The Department of Health at Elephant and Castle.*

252. In his statement dated 22 April 2021 [WITN4500001], Simon Taylor states:

> *[155] The Society developed over time a considerable range of contacts with Government and individuals in public office. It is my understanding that prior to about 1984, contact had been limited to a relatively small number of officials and junior ministers in the Department of Health and these relationships were focussed on the supply of products and principally the issue of self-sufficiency and the development of the facilities at BPL to provide this.*
>
> *[156] When it became clear that we would be calling upon the Government to take action on a wide variety of fronts, particularly support for those infected, the Society started a major campaign of engagement and the recruitment of supporters amongst MPs and also sympathetic journalists.*
>
> *[157] The Society asked all its members to contact constituency MPs and ask for their support for the campaign, and also to feed back to the office any responses, so that the office could maintain a list of supportive MPs.*
>
> *[158] The General Secretary and the Chairman directly contacted government departments to seek meetings with ministers and officials.*
>
> *[159] Over time an 'All Party Parliamentary Group' was formed of MPs and members of the House of Lords and many of these were tireless in their efforts in advocating on behalf of the Society.*
>
> *[160] All contact and relationships were managed through the General Secretary David Watters, and also later Graham Barker, who would report in the first instance to the Chairman Rev Tanner. Virtually all meetings with ministers, officials and MPs were with either David Waiters, together with the Chairman, or Graham Barker, together with the Chairman. It would be highly unusual for any other members of the Executive Committee, including myself, to have any direct communication or contact with ministers, officials or MPs.*

253. Set out below are a number of documents which may assist the Inquiry with gaining a snapshot of The Society's interactions with Government:

   a. Appendix 1 of Minutes of the Meeting of the Council of the Haemophilia Society on 24 November 1984 (Exhibit WITN6392069) which lists issues which would be raised by The Society at a forthcoming meeting with Minister Norman Fowler, which included:

> *1. That since the DHSS have recognised heat-treated product as important enough to bring into production from April 1985 (in small quantities), immediate steps should be taken to import supplies to treat everyone now. The Government will be asked to do this irrespective of cost.*
>
> *2. The Government will be asked to introduce national plasmapteresis programmes to ensure self-sufficiency by 1986. It was noted that while Blood Products Laboratory will have the capacity to achieve self-sufficiency by 1986, the strong evidence was that adequate supplies of plasma could not be obtained otherwise than by plasmapheresis.*
>
> *3. Because of the apparently careless way in which some Transfusion Centres have handled the collection of blood since the AIDS scare began, we will urge that situation to be changed and that the development of the.test for the presence of HTLV-111 in donors /donated blood and blood products be allowed to proceed without financial constraint.*
>
> *4. The Society will, with some reluctance, seek core funding for central running costs from the Department.*

b. Minutes of the Meeting of the Council of The Haemophilia Society on 3 October 1987 (Exhibit WITN6392215) under the heading "Publications and External Relations" at page 3, which notes Andy Cowe's update about upcoming meetings with John Moore, Secretary of State and Parliamentarians at the House of Commons; and summarises a submission that had recently been made to Government and the demands made therein as part of the Parliamentary Campaign;

c. Letter from Lord Skelmersdale (on behalf of the Prime Minister) to David Watters dated 27 October 1987 responding to Mr Watters' letter to seeking compensation for those people with haemophilia who have been infected with HIV through the use of blood products (Exhibit WITN6392216).

d. Minutes of the Meeting of the Council of The Haemophilia Society on 28 November 1987 (Exhibit WITN6392217), which under the heading "Publications and External Relations" at page 2 reports on meetings between a delegation of The Society and Secretary of State, John Moore and Minister of Health Tony Newton on 3 November 1987; and a meeting between a "similar delegation" of The Society and Parliamentarians at a special meeting in the

House of Commons, hosted by Frank Field and Robert Key on 5 November 1987;

e. Minutes of the Meeting of the Council of the Haemophilia Society held on 25 November 1990 (Exhibit WITN6392218) which states under the heading "Compensation update" at page 2 that David Watters reported that following a meeting held in the House of Commons on 21 November 1990, an All Party Group of MPs had been formally established: "*This will be an ad hoc group under the Chairmanship of Patrick Corniack MP, and Vice Chairmen Rosie Barnes, Alf Morris and Jim Wallace. 28 MPs had attended the meeting despite it being a highly fraught day in the House, being the day preceding the resignation of the Prime Minister and the meeting occurring at the same time as a re-scheduled debate on the Disability Bill. It was agreed that, as soon as the new Prime Minister was appointed, everyone should make all possible efforts to write to the new Prime Minister and to the new Secretary of State for Health, William Waldegrave. Mr Watters also paid tribute to the work done by GJW, the Health Network, and his colleagues on the staff at the national office for the work they undertook in connection with the campaign and in supporting his role.*

f. Minutes of The Haemophilia Society's Executive Committee meeting on 8 February 1990 (Exhibit WITN6392219) under the heading "Compensation" at page 1 refer to a "series of parliamentary lunches for small groups of MPs";

g. Minutes of The Haemophilia Society's Executive Committee meeting on 6 June 1991 (Exhibit WITN6392183) under the heading "Whole Blood Transfusion HIV" at page 4 note that David Watters *"announced that he has been invited to speak at an All Party Parliamentary group on AIDS";*

h. Minutes of The Executive Committee of The Haemophilia Society meeting on 14 November 1991 (Exhibit WITN6392155) under the heading "Meeting with Mr Waldegrave, Secretary of State for Health" at page 4 there is a report of the meeting with Mr Waldegrave and David Watters;

i. Minutes of the Haemophilia Society Executive Committee meeting, 13 and 14 October 1995 (Exhibit WITN6392129) under the heading "Hepatitis" at page 5 there is reference to The Society's engagement with Health Minister, Tom Sackville in relation to Hepatitis C funding;

j. Letter from David Watters to the Rt Hon Mrs Virginia Bottomley MP dated 6 November 1992 (Exhibit WITN6392220) regarding concern about the report "The collection and use of human blood and plasma in Europe" by Professor

Van Aken for the Council of Europe and the Commission of the European Communities

k. Minutes of the Haemophilia Society Executive Committee meeting on 29 November 1995 (Exhibit WITN6392221) under the heading "Hepatitis" at page 4 there is an update from Graham Barker about the Parliamentary Campaign relating to Hepatitis C

l. Letter from Gerald Malone, Minister for Health to Chris Hodgson dated 2 December 1996 (Exhibit WITN6392222) regarding financial help for people with haemophilia who have been infected with Hepatitis C.

m. Minutes of Trustee meeting held on 7 November 1997 (Exhibit WITN6392223) under the heading "Hepatitis Campaign" at page 12 refer to The Society having written a letter to Frank Dobson MP, who was at the time Secretary of State for Health.

254. Presently, The Society provides the secretariat to the All-Party Parliamentary Group ("APPG") on Haemophilia and Contaminated Blood. In this role, we maintain the membership information of the APPG and facilitate meetings of the APPG in conjunction with the chairs.

255. The APPG on Haemophilia and Contaminated Blood is a cross party group of MPs and peers who share an interest in bleeding disorders and the contaminated blood scandal. The core purpose of the group is to promote awareness of, and campaign for, people with haemophilia and other bleeding disorders and people infected with blood-borne viruses due to contaminated blood and blood products used in their healthcare treatment. The group is led by Labour MP Dame Diana Johnson and Conservative MP Sir Peter Bottomley alongside 10 vice-chairs and includes MPs from all major parties represented in parliament.

256. The group meets regularly, usually quarterly, to get updates on developments in bleeding disorder care and treatment and on the inquiry into the historical use of contaminated blood and blood products. It often invites ministers and others to address the APPG. It seeks to represent the needs of these communities in parliament and in engagement with Government, Government bodies, the Infected Blood Inquiry and the NHS.

257. The current work of the APPG focuses on:

a. Access to treatment and care for people with bleeding disorders

b. Campaigning for improvements to the Infected Blood Support Schemes
c. The Infected Blood Inquiry and the planned Compensation Framework

258. The APPG has undertaken an inquiry into the current systems of licensing, procurement, commissioning and prescription of treatments for genetic bleeding disorders in the UK. The final report, launched in November 2020, documents the current processes for new and current treatments to become available in the UK with a focus on how these processes impact on the treatments that patients are offered and can be offered by the NHS. It shows where the processes are working well and where they are not. (Exhibit WITN6392224).

259. The group also undertook an inquiry into the support for those affected by the contaminated blood scandal in the UK which was published in January 2015. (Exhibit WITN6392225).

Question 26: What funding has the Society received from the Government since 1970?

260. Please refer to the document which sets out funding received by The Society at (Exhibit WITN6392196). This document includes Government funding received in the 70s, 80s and 90s.

261. The Society currently receives no government funding. The Archer Report into Contaminated Blood and Blood Products in 2009 included a recommendation that the Government should *"secure the future of the UK Haemophilia Society by adequate funding".* As a result, the Department of Health provided a grant of £100,000 per year for five years finishing in 2013/14 to help us provide services to our members. This funding did not continue. Any funding received from Government prior to this time, is set out in The Society's Annual Reports.

262. In his statement dated 3 May 2021 [WITN5252001], Roderick Morrison (who was Trustee of The Society from June 2001 to October 2007; Chair of The Society from June 2003 to October 2007; and Co-Chair of the Haemophilia Alliance from 2008 to 2011) sets out sources of funding received by The Society, including government grants. He notes at paragraph 294 that, *"The sources of funding was broadly stable over my time with the Society although the level of Government grants fell."*

263. Set out below is an extract of the table at paragraph 295 of Roderick Morrison's statement, relating to government grants:

	12/2001	12/2002	12/2003	12/2004	12/2005	12/2006	3/2008 15 months
Government grants	158,000	125,000	115,000	110,000	110,000	107,500	97,500

264. The Society has also received grants from government for its work related to HIV and AIDS. By way of example, Minutes of the meeting of the Council of The Society on 10 March 1985 note that The Society was awarded *"a grant of £15,000 under section 64 of the Social Security Act to assist with [The Society's] extra workload relating to AIDS"* (Exhibit WITN6392226).

265. Minutes of a meeting of the Council of The Haemophilia Society dated 18 March 1989 (Exhibit WITN6392080) record that *"following an application for a grant of £50,000 to cover an anticipated shortfall of that sum in the financial period ending 31 December 1988, the Government had, in recognition of the work carried out by the Society in relation to HIV and AIDS, given a grant of £35,000 for the 1988/89 period. In addition, they would be considering an application for a further £50,000 in respect of funding of a Resource Health Advisor who it was hoped would be appointed during the financial period 1989/90. It was hoped that the person so appointed would be able to equalise the provision made for people with haemophilia and HIV throughout the country".*

266. The Society also supported many NHS costs, for example, staff costs and equipment, as can be seen in this following documents:

a. Between 1988 and 1993, £10,300 was contributed for the employment of physiotherapists in Bristol, Leeds and Truro (see Minutes of the Meeting of the Council of The Society on 23 September 1989 at page 5 (Exhibit WITN6392081); Minutes of the Meeting of the Council of The Society on 24 November 1991 at page 4 (Exhibit WITN6392091); and Minutes of the Executive Committee held on 29 to 31 October 1993 at page 5 (Exhibit WITN6392227).
b. Between 1989 and 1991, £11,000 was contributed to Haemophilia Centre facility improvements at Addenbrookes, Margate, Sheffield and Oxford (see

Minutes of the Meeting of the Council of The Society on 18 March 1989 at page 5 (Exhibit WITN6392080); and Minutes of the Meeting of the Council of The Society on 24 November 1991 at pages 4 and 5 (Exhibit WITN6392091).

c. The News Bulletin dated October 1976 (Exhibit WITN6392228) notes at page 1 that: *"It is sometime said that we may be providing money for projects which should be paid for by the National Health Service but we usually reach the point where, unless we give support a particular project may founder. Also, it is a fact that Haemophilia Society money has initiated projects or appointments and when, after one or two years their success and usefulness is seen, the responsibility is taken over by the local Health Authority."*

Question 27: Did the Society have any concerns, at any time, about challenging the Government in case the funding received might be withdrawn? If so, please set out what the impact was and what the Society chose not to challenge because of those concerns.

267. I have not seen any documented evidence to support this. However, based on the documents I have seen (particularly The Society's letters to government), I am aware that The Society has never stopped lobbying government in its history. Margaret Unwin's very direct correspondence with Mr Connon at the Blood Policy Team in 2006 (Exhibit WITN6392229) does not suggest any reticence in challenging civil servants arising out of perceived financial jeopardy.

268. We have received little funding from government and as such, there has never really been a need not to be forthright in our representations to government. Our decades of campaigning in relation to contaminated blood is strong evidence that we have never shied away from challenging government.

Question 28: When campaigning for financial recompense in relation to both HIV and HCV, the Society described the case against the Government as being a moral case, rather than a legal case. What was meant by this?

269. The May 1987 issue of The Society's publication, *Haemofact* (Exhibit WITN6392230) which focusses on A review of the position of the position on compensation and insurance for haemophiliacs sets out The Society's position as follows:

> ***The Society's Position***
>
> *In this issue of Haemofact we want to make it quite clear that it is the Executive Committee's unanimous and strong view that people with haemophilia who are HIV positive deserve special financial support from the Government.*
>
> *Even if legal responsibility is unclear the Government has a clear moral duty to provide recompense for the additional financial burdens, the hurt and worry now being suffered as a direct result of receiving infected blood products. The extent of the HIV problem would have been considerably reduced if successive governments had honoured their pledges to make the UK self- sufficient in blood products and if steps had been taken sooner to screen donations and heat-treat the products.*
>
> *The Society has committed resources, both of time and money, in investigating the most effective means of obtaining recompense.*
>
> *We are now able to give more details of how we can pursue our claim against the Government.*
>
> *The legal advice, explained in Haemofact 12, makes it clear that there is no case for the Society itself to act on behalf of our members, either corporately or individually. However, we repeat that WE WILL BE HAPPY TO GIVE ANY INFORMATION we have in support of any member who wishes to raise a personal action. Individual cases are under way which we have assisted in this way. We will keep you informed of any developments.*

270. I also refer the Inquiry to the oral evidence of Simon Taylor who was asked about this point when he gave evidence to the Inquiry on 26 May 2021:

> *MS FRASER BUTLIN: In relation to both the HIV and hepatitis C campaign, you've described it as being a moral case –*
> *A. Yes.*
> *Q. -- rather than a legal case. Can you explain what you mean by that?*
> *A. The moot cause of the reason we're all here today is that -- is that I and the Society has always believed that it was a failure in Government policy. Dr David Owen made the commitment and has given evidence to this Inquiry; he made*

> *the commitment in the mid-1970s. And as a physician himself, he recognised the dangers and problems of the blood supply that was coming from the United States, and I think that was a key motive -- well, I know that was* a key motivation of him making that policy*, in discussions I've had with him. And it was that consistent failure over many years by governments of varying different colours to implement that promise, which, if implemented, might not have eliminated all of the problems that we've had to deal with but would have vastly mitigated those -- the number of people infected and affected, by a considerable amount. And so, consequently, we believed that the Government on the day -- or all governments -- had a moral responsibility to redress the failure to implement that Government policy.*

271. I would also like to draw the Inquiry's attention to the fact that the need for those who have suffered injury as a result of ill-advised medical products prescribed by the NHS to appeal to a moral, rather than legal, obligation on the part of government as a result of litigation being too difficult, is far from historic. I refer here to the Sunday Times' report on the investigation into the use of the epilepsy drug sodium valproate on 22 May 2022. This reports that Baroness Cumberlege has commissioned a report about past government financial support schemes for victims of vCJD, contaminated blood and vaccine damage. Further that she has suggested that a trust could be established with an initial £20 million and that last week she told the House of Lords that: "*We must accept in any decent society, we have a moral and ethical duty to provide help to people whose lives have been ruined and who suffer constant emotional turmoil through no fault of their own…The system failed them and we have a duty to help them…the government has so far refused to help, saying the focus is on preventing future harm…*" The newspaper report also states that ministers have suggested that affected families bring clinical negligence claims despite being told that claims have had to be dropped "because it was the regulators that kept information from patients and doctors for years." (Exhibit WITN6392231).

Question 29: The word 'hardship' was used extensively by the Society during the campaign for financial recompense. On 28 September 2001 it was decided that the word would not be used [HSOC0029689_040]. What were the views of members about the issue? How had the views of members about the issue been conveyed to the Executive Committee? Why was the word dropped?

272. In a document titled *"Haemophilia and Hepatitis C – The Case for Financial Recompense: Special briefing for Members of Parliament"* dated January 1998 (Exhibit WITN6392232) there is reference to advantages of a "hardship fund" at page 3:

> ***b) Access to a hardship fund***
> *A hardship fund has the advantage of being able to target help to those with specific needs arising from their HCV infection. It has the flexibility to make one off single payments, for example to pay for respite care, whereas regular monthly payments could help top up income reduced by the need to work fewer hours because of illness. A hardship fund could also make payments in specific circumstances such as bereavement or for extra heating in winter.*

273. Minutes of an Extraordinary Trustee Meeting on 19 January 2001 (Exhibit WITN6392233) note that the objectives of the Hepatitis C Campaign would "exclusively" be:

- *a public inquiry into blood borne infections*
- *a hardship fund which would be a fixed total sum for the benefit of individuals affected by HCV on a case by case basis on evidence of hardship*
- *recombinant for all*

274. At page 7 of the Autumn 2001 edition of The Bulletin (Exhibit WITN6392234) there in an article relating to "Questions and answers" about The Society's campaign for financial recompense. The following explanation is given about the use of the term "hardship fund":

> *Why is the Society campaigning for a 'hardship fund'? The Society's communications and public affairs advisors have chosen the term 'hardship fund' as a means of conveying the message that infections passed on through contaminated blood products are causing actual hardship. And at the same time, that some sort of special fund needs to be set up for the purpose of providing financial help. The Society does not rule our other forms of financial help – including compensation, of course. However, we are aware that the normal route to compensation is through the courts of law and legal process. The setting up of a special fund would be a very different process, involving a*

> *political decision by government and MPs – as happened when the Macfarlane Trust was created as a special political initiative with all-party support. Our message is that the tragedy of contaminated blood products needs to be addressed now, with funds made available as a matter of urgency to enable those affected to have the best possible quality of life.*
>
> *Would any fund be means tested? The Society accepts that the use of the phrase 'a hardship fund based on evidence of need' has caused some confusion. The 'need' referred to in this phrase is clinical need, just as is used in applying for money from the Macfarlane Trust. The Haemophilia Society has been careful to note the objections from our membership concerning means testing and stresses that we have no intention of proposing a means tested scheme to Government."*

275. It may also assist the Inquiry to refer to the evidence of Karin Pappenheim on 27 May 2021, when she gave evidence about the terminology "hardship fund". When asked whether a phrase such as "hardship fund" might lead people to think it's talking about specific financial hardship, which might then connote ideas of means testing, Ms Pappenheim responded:

> *I suppose you need to go back to what it states in the earlier paragraph* [of WITN10055709], *that in 1996 the Society commissioned this report on the impact of hepatitis C, the Mandy Cheetham report, and one of the recommendations was the setting up of a hardship fund. So I would say that already, from 1996 onwards, the proposal for a hardship fund, if you like, was in the public domain as a recommendation. And it would also be, I think, entirely correct to say that people affected by hepatitis C were suffering hardship. And that is a perfectly legitimate word to use, I believe, because we were illustrating in many ways the kind of hardship, ie, if you've lost employment for instance, if you were financially less well off than you were before the impact of the virus, that is hardship. And those were the terms we used at the time. So we never understood by that any form of means testing. The term was used in recognition, I believe, of the fact that hardship was being experienced. And in arguing the case for a fund, it would be very important to establish in the minds -- again, it's politicians we have to persuade, this has had a huge impact, economic, social, on people who are infected with this virus. That is hardship. And it's hardship that needs to be recompensed, as it were. But it would be*

> *rather a leap from that to assuming that "hardship fund" would mean means testing. That was not our intent.*

276. By way of background, I draw the Inquiry's attention to a document which includes extracts of House of Commons debates regarding haemophilia, spanning from May 1989 to April 2006 (Exhibit WITN6392235). In these parliamentary debates, there are several examples of the challenges or "hardship" suffered by people with haemophilia who have been infected with blood products (see extracts from debates on 25 January 1996; 22 May 1996; 16 December 1996); and there are also references to the "hardship fund" which The Society campaigned should be set up by the government (see extracts from debates on 15 March 1995; 13 December 1995; 24 June 1997; 18 November 1998; 30 April 1999).

277. When Karin Pappenheim gave evidence to the Inquiry on 27 May 2021, she was asked about use of the terminology "hardship". In the context of responding to questions about the Summer 2001 (No. 2) edition of The Bulletin (Exhibit WITN6392105) she was asked why the term "hardship fund" was used. She responded:

> *I think it's -- at this point where we are currently, at such a distance of time, from my current recollection, sitting here today, what the reason was, for choosing that word, "hardship", I don't think I can explain that by memory. I don't know that I can comment further as to why. The only comment I would make is that when we stated campaign aims, which, as you've seen in the documentation to date, on a number of occasions, there were different words used, going right back to even before I joined the Society, different words were used at different times to explain what the campaign aims were. And those words would have been chosen for clarity of communication to our members, but also very much to those that we were trying to influence. So it's possible that -- this is only speculation, but using that word, "hardship", may have been felt to be a clearer way of explaining that. That's only speculation today so I'm sorry I can't from memory explain why that change of word.*

278. Correspondence and emails dated from July 2000 to August 2001 between members, The Society's Chair and Executive Committee illustrate disagreement as to use of the term "hardship fund". This correspondence may have influenced why the term "hardship fund" was discontinued from use in September 2001. The Inquiry is in

possession of this correspondence and The Society can point the Inquiry to these documents if it would be helpful to the Inquiry.

279. As noted in the Inquiry's question, Minutes of Board of Trustees Meeting held on 28 September 2001 (Exhibit WITN6392236) record The Society's decision to stop using the term, "hardship fund" as follows:

> *(b) Campaign Meeting: There was discussion on the campaign meeting held on 11th September with representatives of the Society's groups and outside groups with an interest in the campaign. Some trustees expressed concern that only six of the Society's own groups had sent a representative to the meeting.*
>
> *It was also noted that, as this was a meeting of groups representatives only, it had not included all the many individuals around the country who actively support the campaign, and that if future meetings were held on the campaign it would be beneficial to include these individuals as well. It was noted that discussion during the meeting had revealed that most supported the three campaigning aims of the Society. However, strong feeling had been expressed about the term "hardship fund" and the Society had therefore agreed to drop the use of the word "hardship" in future.*

280. I understand that there was also internal uses of the term "Hardship Fund" which do not relate to The Society's campaign for financial recompense. The internal or other use of the term "Hardship Fund" is explained in a document prepared by Ruth Taylor dated in 26 July 2004 (Exhibit WITN6392237):

> *The Hardship fund has been in existence, to the best of my knowledge, for at least 12 years and became the Alan Tanner Hardship Fund in 1997 in recognition of his work as chairman of the Society for many years. I only have records going back to the beginning of 1998. At that time it had an annual budget of £10,000. Its current budget is £11,000. It meets every two months and its budget per meeting is £1,833. Generally there is a maximum individual grant of £500. This has not changed since 1998.*
>
> *The Hardship Fund assists people affected by haemophilia with the cost of essential items (preferably directly related to haemophilia) which they cannot afford themselves. Applicants must be on a low income though they do not*

have to be on income support levels. We only accept one application per family per year. The Grant Committee consists of the Chief Executive, the Fundraising and Marketing Manager and the Treasurer. Applications are anonymised when presented to the Committee. All applications are in writing on a form and must be supported by a healthcare professional from the treatment centre attended by the applicant.

We don't normally consider applications for the following:

- *Holidays as there are charities specifically devoted to providing these*
- *Deposits for Motability cars because the Motability scheme provided assistance towards deposits and many cars do not require deposits. However, recently Motability has refused to fund the first £500 of deposits so where a strong medical case can be made for requiring a car with a deposit we are sometimes funding these*
- *Driving lessons as these can be funded by the Motability scheme*
- *Ongoing bills e.g. gas, electricity etc.*
- *Hospital travelling expenses when these can be met through the benefits system.*

We have helped provide fridges, cookers, beds, bedding, washing machines, carpets, sofas, and made contributions to the costs of funerals among other things. Sometimes we have identified that people are not claiming their full entitlement to benefits. Where we are unable to help we can often suggest other sources of help and sometimes help with applications.

281. This alternative context in which the term "hardship fund" was used is also referred to in The Society's Minutes of the Board of Trustee Meeting on 24 July 1997 (Exhibit WITN6392238) as follows at page 2:

T97.29 Tanner Fund for Hardship
The Chairman reported that it had been propose d that the Society re-names its Financial Assistance Fund (Budget item 7606 on Expenditure Report) to the Tanner Fund for Hardship and accepts payment into that fund from other sources. Nick Lawson spoke in support of the proposal.

> *Mary Clark questioned the use of the word "hardship" and suggest ed that it may deter people from applying for assistance. Following further discussion Gordon Clarke proposed that the matter be referred to the Resources Committee for the agenda for their first meeting. The motion was seconded by Nick Lawson and agreed unanimously.*

Section 6: Other Issues

Question 30: Please explain, in as much detail as you are able to, any other issues that you believe may be of relevance to the Inquiry.

Recombinant for all campaign

282. 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.

283. A letter from Graham Barker (Director of Services and Development) to Members of The Society dated 22 August 1996 (Exhibit WITN6392239) 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.

284. 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 WITN6392240);
  b. Minutes of the Haemophilia Society Executive Committee meeting on 29 November 1995 under the heading "VAT on Recombinant Products at page 2 (Exhibit WITN6392221);
  c. An article titled "VAT on Recombinant FVIII" at page 3 in the December 1995 edition of The Bulletin (Exhibit WITN6392098) 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 WITN6392190);
  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 WITN6392193);
  f. Minutes of the Board of Trustees Meeting dated 16 April 1997 under the heading "Services/Campaign Updates" at page 3 (Exhibit WITN6392241);
  g. The Society's Minutes of the Board of Trustee Meeting on 24 July 1997 (Exhibit WITN6392238) 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 WITN6392242);
  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 WITN6392243);
  j. Letter from John Latimer to John Hutton, Minister of the Department of Health dated 16 April 2001 (Exhibit WITN6392244).

Funding research

285. A key focus for The Society has been funding research for many decades the details of which are recorded in the Executive Committee meeting notes as can be seen by the noted actions in 1982 to set up a research appeal (see notes of Executive

Committee meeting on 11 March 1982 (Exhibit WITN6392245). Up to 1982, £172,474 had been spent on research projects to support a variety of projects, including funding staff placements, purchasing equipment and research into new products and care (see notes of Executive Committee meeting on 6 April 1982 (Exhibit WITN6392246). From April 1983, research grant applications began to be received in respect to work looking into AIDS Many grants to support AIDS research were granted including to the Public Health Laboratories Services (see notes of Executive Committee meeting on 15 March 1984 (Exhibit WITN6392247).

286. A document titled "Research/Grant Applications", considered at the meeting of the Council for The Haemophilia Society on 16 April 1988 (Exhibit WITN6392248) records the decision making process in the introduction at page 2:

> *Grant applications are received at the national office twice each year - closing dates for such applications being 1 January and 1 July. Those applications are, first of all, considered by a sub-committee of the Executive Committee (in fact the Chairman, Vice-Chairmen and Treasurer). This sub-committee reports to the Full Executive Committee who determine the recommendations which will be made to the Council in respect of each application.*
>
> *Details of the applications received and the recommendations which will be placed before the Council are listed below and overleaf.*

287. I have considered a number of documents that demonstrate some of the research that The Society funded or supported on behalf of 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 not only research but also written publications, workshops, lectures, 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.

   a. At page 5 of The Society's November 1993 edition of The Bulletin (Exhibit WITN6392249), 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.

b. On the front page of The Society's April 1994 edition of The Bulletin (Exhibit WITN6392156) there is an article titled "Hepatitis C – A cause for concern?" written by Simon Taylor. 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.*"

c. The Society's March 1995 edition of The Bulletin (Exhibit WITN6392103) 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. 1995 also saw publication of The Society's book on Haemophilia and Hepatitis C. Documents reporting on these events are set out below. The Hepatitis booklet, titled "Haemophilia and Hepatitis C" was published in 1995 (Exhibit WITN6392250). 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."*

d. The Minutes of The Society's Services Committee meeting, 16 November 1995 (Exhibit WITN6392251) makes reference to the following work The Society was doing in relation to Hepatitis C, HIV and blood products: 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); Mandy Cheetham would produce a number of fact sheets; The HIV Task Group discussed Guidelines on Good Practice for HIV Treatment and content for future editions of The Bulletin (at page 3);

e. The Society's Haemophilia and Hepatitis C Research Report by Mandy Cheetham (Exhibit WITN6392252) 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*".

f. The Society's first 1997 edition of The Bulletin (Exhibit WITN6392193) refers to the following information relating to hepatitis C and HIV: An article on protease inhibitors for HIV (at page 9); An update on the Hepatitis C Handbook (at page 12);

g. 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 WITN6392253).

288. Exhibit WITN6392254 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 and AIDS. 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 Campaign 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 — Hepatitis 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 Campaign. (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.

289. The list of publications referred to in my response above, coupled with the extensive (but certainly not exhaustive) actions described in this statement 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 AIDS and hepatitis C. It is clear from the selection of references and documents set out above that The Society has been determined to extensively campaign, advocate and fight to help make the voices

of people with hepatitis C or AIDS/HIV be heard by government decisions makers, the courts and the wider community.

Self-sufficiency

290. For many years, The Society has strongly campaigned for achievement of self-sufficiency in blood products. A review of the Executive Committee meeting minutes shows that dried concentrates were discussed at the 1969 World Federation of Hemophilia Congress. Mr Schnabel had had discussions with commercial producers with the idea that they produce concentrates in more countries, reduce the price of FVIII and IX and make their profits primarily from the remaining blood constituents. The Congress agreed with that and agreed to encourage transfusion services to make dried concentrate wherever possible (see Minutes of the Executive Committee of the Haemophilia Society on 28 August 1969 (Exhibit WITN6392255)).

291. The Society was then concerned about the supply of FVIII concentrates from at least July 1972. A committee meeting was then joined by Dr Dormandy to discuss a Society produced report on the topic and she suggested that the Society liaise with Dr Biggs. The Society continued to gather data about shortages at different centres. In 1974, The Society supported Dr Biggs' appeal for an increase in supplies and had had a letter published in the Lancet. (See Minutes of the Executive Committee on 10 August 1972 (Exhibit WITN6392256) and 8 August 1974 (Exhibit WITN6392257)).

292. There was a publicity campaign to highlight the issue and £2,000 was donated. There was a meeting with the Medical Advisory Panel (the Department of Health and Social Services having bought 500,000 units of commercial concentrate) to discuss supply. The Society attended a meeting of Centre Directors where home treatment was discussed. (See Minutes of the Executive Committee on 10 October 1974 Exhibit WITN6392258) and partial Minutes of the Executive Committee on 12 December 1974 Exhibit WITN6392259).

293. In due course, the Society wrote to the Minister for Health Dr David Owen requesting a meeting and was pleased when he agreed. The relevant part of the meeting was reported in the Society's 11 December 1975 Executive Committee's meeting minutes (See Exhibit WITN6392260) as follows:

> *Dr Owen stated that in 1977 we would be fully self-sufficient in concentrates. The whole question of commercial concentrates, plasmapheresis, the regional structure of the BTS and other matters were fully discussed. Regular contact was to be maintained in the future and annual meetings held to discuss haemophiliacs' problems.*

294. A number of other documents which record some of The Society's work for achievement of self-sufficiency in blood products include:

   a. Briefing paper for meeting Dr Gerard Vaughan dated 21 October 1981 seeking clarity over whether self-sufficiency is still Departmental Policy; and asking questions about this (Exhibit WITN63922261)
   b. Letter from David Watters to Mr Green from the Department of Health and Social Security dated 15 August 1983 (Exhibit WITN6392262)
   c. Lecture delivered by Dr S E Lane, Director, BPL to The Society on 1 March 1986 regarding self-sufficient manufacture of Blood Products in England and Wales (Exhibit WITN6392263)
   d. Letter from G E Whittaker, Regional Scientific Officer of the Northern Regional Health Authority to David Watters dated 4 April 1986 (Exhibit WITN6392264) responding to Mr Watters' letter in which he expressed concern at the Northern Region's performance in respect of the amount of plasma sent to Elstree.
   e. Note from Ken Milne dated 11 October 1987 *"wonder[ing] if we should not have pester BPL and the DHSS more about the continuing delay in achieving self-sufficiency – this would not, of course, advance self-sufficiency by any significant period, but might give us a tactical advantage in any future demands we might make. It seems possible, for example, that we will be asking for monoclonally—purified products before long, a request which will not be terribly popular. As this is to a large extent a P & E R matter, I think it would be helpful if we could establish a more formal liaison between me and the P & E R working party."*
   f. Letter from David Watters to Dr John Cash of the Scottish National Blood Service dated 6 July 1988 (Exhibit WITN6392265)
   g. Note regarding meeting with Mrs Edwina Currie, the Junior Minister, to discuss UK self-sufficiency in Factor VIII on 2 December 1988 (Exhibit WITN6392266)
   h. Letter from the Chief Medical Officer of the Department of Health to David Watters dated 1 November 1990 confirming that "since 1976 it has been government policy that the UK… should be self sufficient in blood products" (Exhibit WITN6392267)

295. 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 WITN6392059).

Closing remarks

296. We were founded by two patients as a result of a conversation at St Thomas' hospital in 1947 and we will always continue to be true to our founders and be a patient and member led organisation. We work proudly alongside others in the NHS, pharmaceutical companies and other haemophilia organisations, but we will never stop putting our members' interests first.

297. We began life as an organisation targeted at haemophilia. We have grown into an organisation who very much in our heart represent people with infected blood and all genetic inherited bleeding disorders. We have adapted to devolution, and an aging membership, we promote diversity, women's bleeding disorders, equality and the best treatment/ healthcare for all of our members and we have managed all of this alongside campaigning for victims of the worst treatment disaster in the history of the NHS.

298. As a small charity we have had to contend with the biggest treatment disaster in the history of the NHS. We have had to fund for the most part all of our work and much of our work has been undertaken by volunteers whilst also fighting the impact of their own infections and bleeding disorder.

299. The impact of the contaminated blood scandal has inevitably had an enormous influence on the work, strategic thinking and values of The Society over the last four decades. The scale of the tragedy that engulfed our community cannot be underestimated and at times, it has been a challenge to ensure that the diverse needs of all our members were met to everyone's satisfaction – as the letters to the editor in the fourth edition of The Bulletin in 1998 illustrate well.

300. Today this challenge persists. At a time of great financial challenges for all charities, we continue to have as a key priority the need to invest time and resources in the

Infected Blood Inquiry and the support of those impacted. I consider this to be an essential, non-negotiable part of our work. However, the needs of our members untouched by the scandal are equally important as we strive to support our whole community as summed up as "Together for Life". We will continue to work to bring our community together in recognition of what has happened and the need to move forward with clear answers about what went wrong in the past and to shape a better future for all.

Statement of Truth

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

Signed **GRO-C** ________

Dated 9th August 2022