Witness Name: Hayman, Baroness Helene
Statement No.: WITN5523001
Exhibits: WITN5523002 - WITN5523024
Dated: 12 September 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF HELENE HAYMAN

I, Baroness Helene Hayman, will say as follows: -

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Section 1. Opening Comments

1.1. My name is Helene Valerie Hayman (Baroness Hayman, of Dartmouth Park). My date of birth is GRO-C 1949 and my address is known to the Inquiry. I was Parliamentary Under-Secretary of State for Health in the Lords between 28 July 1998 and 29 July 1999. I provide this statement to the Inquiry in response to a Rule 9 request dated 24 June 2022 and I follow the section headings in the Inquiry's request.

1.2. I am mindful that the events to which the Inquiry refers took place over twenty years ago and, as such, I have very limited independent memory of my individual thoughts and actions. For the most part, my statement is a reconstruction of events based on the documents provided by the Inquiry and made available to me by the Department of Health and Social Care ("DHSC").

1.3. My only clear recollection is the conversation that I had with Frank Dobson, then Secretary of State for Health, on my first day as Parliamentary Under-Secretary of State for Health. As referred to in further detail at paragraph 6.6 below, Mr Dobson recognised that the decision not to set up a special payment scheme for those suffering from Hepatitis C was an emotionally charged and difficult one and he felt that it was unfair for me to make the public announcement given that I had not been involved in the decision itself.

Section 2: Introduction and Professional History

2.1. I am asked about my professional qualifications and to provide a brief overview of my career. I hold no professional qualifications relevant to my role as Parliamentary Under-Secretary of State for Health. I did, however, hold various roles in the NHS over the course of more than twenty years.

Career Overview

2.2. As an undergraduate, I studied law at Newnham College, Cambridge although I never qualified as a practising solicitor or barrister. After graduating from University, I worked for Shelter from 1969 to 1971, and in the Social Services department at the London Borough of Camden and National Council for One Parent Families from 1971 to 1974.

2.3. I was elected to Parliament in 1974 as the MP for Welwyn and Hatfield, a seat I held until 1979.

2.4. Following my time as an MP, I held a number of positions relevant to healthcare, including:

(1) I was a member of the Bloomsbury Health Authority (latterly the Bloomsbury and Islington Health Authority) from 1985 to 1992, and its vice-chair from 1988 – 1990; from 1992 to 1997, I was a member of the Council of University College, London and chair of the Whittington Hospital NHS Trust; and,

(2) I served on the ethics committees of the Royal College of Gynaecologists from 1982 to 1997 and of the University College London and University College Hospital from 1987 to 1997.

2.5. On 2 January 1996 I was made a life peer. After the Labour party won the 1997 general election, I held the following posts in government:

(1) **6 May 1997 – 28 July 1998**: Parliamentary Under-Secretary of State for Roads, Department for the Environment, Transport and the Regions.

(2) **28 July 1998 – 29 July 1999**: Parliamentary Under-Secretary of State for Health, Department of Health ("DH").

(3) **29 July 1999 – 7 June 2001**: Minister of State, Ministry of Agriculture, Fisheries and Food ("MAFF").

2.6. After leaving government, I was chair of Cancer Research UK between 2001 and 2005. I was also a trustee of the Royal Botanic Gardens, Kew between 2002 and 2006, and a trustee of the Tropical Health and Education Trust between 2005 and 2006. I was also a member of the Human Fertilisation and Embryology Authority from 2005 – 2006 and the inaugural chair of the Human Tissue Authority from 2005 – 2006.

2.7. In the House of Lords, I was a member of several committees:

(1) **3 December 2003 – 8 November 2006**: Liaison Committee (Lords),

(2) **30 November 2004 – 7 April 2005**: Lords Select Committee on the Assisted Dying for the Terminally Ill Bill.

(3) **1 December 2004 – 8 November 2006**: Constitution Committee.

(4) **27 November 2006 – 5 September 2011**: Procedure and Privileges Committee.

2.8. On 4 July 2006, I was elected as the first Lord Speaker and I had this role until 31 August 2011. On my election, I resigned my membership of the Labour party and have since sat as a crossbench peer. My main interests since 2011 have been international health and climate change.

2.9. I am asked if I have, or had, any memberships of or involvements with any committees, associations, parties, societies, groups or organisations relevant to the Inquiry's Terms of Reference. The roles I held in health organisations that I have mentioned above may fall into these categories but I cannot think of anything else that I have not already mentioned.

2.10. I am asked to provide details of any business or private interests which are relevant to the Inquiry's Terms of Reference. My Register of Interests for the House of Lords is publicly available but I do not consider that any of them are relevant to the Terms of Reference of this Inquiry.

2.11. I am asked whether I have provided written or oral evidence to, or have been involved in, any other inquiries, investigations or proceedings in relation to 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. I have not.

Roles and responsibilities as Parliamentary Under-Secretary of State for Health

2.12. Prior to my appointment, Baroness (Margaret) Jay had been the Health Minister in the Lords (as a Minister of State).

2.13. When I took up the role of Parliamentary Under-Secretary of State for Health in the Lords, the ministerial team was as follows:

(1) Secretary of State: the late Frank Dobson;

(2) Minister of State for Health Services: Alan Milburn, who was succeeded by John Denham on 30 December 1998;

(3) Minister of State for Public Health: the late Tessa Jowell; and

(4) Parliamentary Under-Secretary of State for Health (Commons): Paul Boateng, who was succeeded by John Hutton on 27 October 1998.

2.14. During the twelve months that I was Parliamentary Under-Secretary of State for Health in the Lords, I had delegated responsibility for a number of policy areas including, blood and transplant services, NHS litigation, preparations for “Y2K”, waiting lists and the pharmaceutical price review scheme. Unfortunately, I do not have access to the fuller list of my portfolio of responsibilities and I am advised that searches by my legal representatives have not yielded any further results.

2.15. Upon my promotion to Minister of State at MAFF, my successor as Parliamentary Under-Secretary of State for Health in the Lords was Lord (Philip) Hunt.

Section 3: The Alliance House Organisations

3.1. I should start by saying that "Alliance House Organisations" ("AHOs") is not a term that I am familiar with. I am told that it was a term that was not in use at the time I was Parliamentary Under-Secretary of State for Health and only came to prominence later on.

3.2. Generally, there tended to be little formal generalised briefing for junior ministers. We would tend to learn about issues as and when they arose and we were briefed on them by officials. I have no specific recollection of being briefed on the AHOs.

3.3. I am asked about the involvement I had with the AHOs in my role as Parliamentary Under-Secretary of State for Health, including which issues were brought to me as the minister and which issues were dealt with without my involvement, and my understanding about how these decisions were made.

3.4. I would have expected officials and relevant stakeholder organisations such as the Macfarlane Trust to liaise sufficiently often so as to be aware of significant developments and areas of concern. Matters such as the liaison over administrative funding arrangements (under s.64) would ordinarily have been dealt with by officials, though depending on the size this may have required ministerial sign-off. For example, the minutes from the Macfarlane Trust trustee meeting held on 12 July 1999 indicate that there was an issue with the slow provision of S.64 funding that year [**MACF0000017_068**]. This kind of issue would have been dealt with by officials and I would not have been involved in any related communications. Issues concerning significant new spending / capital funding would usually have required ministerial approval (or at least I would have expected them to). Other issues might need to be escalated to ministerial level but this would be fact-sensitive to what the issue was and whether officials were able to resolve it.

3.5. I am asked how frequently I met with the chair and trustees of the AHOs and the rationale for this frequency. So far as I can tell from the documents provided to me, I personally met the Macfarlane Trust on one occasion during my twelve month period as Parliamentary Under-Secretary of State for Health. That meeting was on 17 June 1999 when I met the chair of the Macfarlane Trust, Rev'd Alan Tanner and trustees. I do not now recall this meeting.

3.6. I have been referred to a note of the meeting on 17 June 1999, which concerned the Macfarlane Trust Strategic Review **[DHSC0003212_005].** The Inquiry has asked me about the Macfarlane Trust Strategic Review and I refer to further documents relevant to the meeting and the Strategic Review in section 4, below. However, regarding the frequency of meeting with the Macfarlane Trust, the note recorded that going forward, ministers would have an annual stocktake meeting with the Macfarlane Trust and that officials would meet with the Macfarlane Trust three times a year.

3.7. Also, on 1 July 1999, I wrote to the Rev'd Tanner **[DHSC0006162_006]**[1]. As regards the frequency of meeting, I wrote,

> *"I would be very happy to meet with you annually to "stocktake" any outstanding issue and to offer help where I can. This does not mean, of course, that we cannot meet before that year is up, but it seems reasonable to start with the aim of meeting once a year. There are some residual issues, including full notification of the S.64 grant and the appointment of Trustees, which officials will be completing and discussing with you, consulting Ministers as appropriate."*

As this letter made clear, I was not seeking to restrict meetings to one per year, should a particular need arise for an additional meeting. However there was good sense in having a baseline arrangement of meeting at least once per year at ministerial level, with more frequent meetings with officials. I think the general rationale for an annual meeting was that it helped provide reassurance that this was an ongoing relationship that the Macfarlane Trust had with us. My reading of the document is that prior to my involvement, a regular pattern of meetings had not been established. In my previous ministerial role, I had found that it was

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[1] The Inquiry has also supplied me with what appears to be a draft of this letter: **[DHSC0003232_007]**.

good practice to schedule regular meetings with relevant organisations rather than waiting for a crisis to occur for first contact to be made.

3.8. The Inquiry has referred me to the minutes of a meeting of the trustees of the Macfarlane Trust dated 12 July 1999 **[MACF0000017_068]**. I would not have seen these minutes at the time. The minutes record the Rev'd Tanner's report on our meeting on 17 June in the following terms:

> *"The Chairman reported that the meeting with Lady Hayman had taken place in mid-June. It had been an excellent meeting, with each Trust representative presenting their piece, and Lady Hayman carefully listening to all that was said, showing real interest in each presentation. The atmosphere had been good, and the team came away well satisfied with what had taken place. A subsequent letter from Lady Hayman had been circulated to all Trustees, and a further meeting with Civil Servants was planned for the Autumn"*

The reference to a subsequent letter from me is likely to be a reference to my letter of 1 July 1999.

3.9. I am unable to recall what contact I had with the beneficiaries of the AHOs during my time in office. So far as I can recall, my face to face dealings were with the chairman and trustees rather than through specific meetings with beneficiaries (although the Rev'd Tanner was himself the father of a haemophiliac who had died from contaminated blood products). My letter of 1 July 1999 captures, I believe, the sense in which my meeting with the trustees had made a greater impression than written correspondence could. So meeting the Trust in person would have helped me better to understand the needs of the beneficiaries. Other sources of information about the needs of beneficiaries would have included: briefings from officials, dealing with Parliamentary Questions, and ministerial correspondence. Issues were often raised formally and informally by peers who were involved with certain topics. Lord Morris of Manchester was particularly concerned with the matters covered by this statement.

3.10. I would add that Lords do not have constituents in the same way that MPs do, so we do not tend to see the kinds of things that are raised every day by people through that route. I would expect that by virtue of their role, a lot of MPs were frequently in touch with the beneficiaries in a way that I would not have been. As Parliamentary Under-Secretary of State, however, I would have seen correspondence from MPs, sometimes including letters they had received from constituents (as set out in further detail at paragraph 6.2(43) below). When individual members of the public wrote into the department, they would usually be dealt with by officials and would not come across a ministerial desk.

Section 4: The Macfarlane Trust Strategic Review

4.1. I am asked to comment on the Strategic Review prepared by the Macfarlane Trust in 1999. As set out in my opening comments, I have no independent memory of the Macfarlane Trust Strategic Review and, as such, this section is a reconstruction of events based entirely on the documents made available to me.

4.2. I am referred by the Inquiry to a number of documents in relation to the Strategic Review:

(1) The covering letter dated 29 January 1999, sent to me by the Rev'd Tanner, enclosing a copy of the Strategic Review **[DHSC0032142_009]**. This has an endorsement in hand indicating, *"Minister to see [and] then advice from officials. I have the working papers binder if you want to look at it. Janet."* Janet Gordon was a member of my Private Office when I joined the department. This note suggests that I would have been provided with sight of the report on its arrival, with advice from officials on it to follow. It is unclear whether I would have seen the working binder. The Rev'd Tanner's covering letter highlighted the increasing life expectancy of those haemophiliacs infected with HIV and the complications and adversity created by co-infection with Hepatitis C. The sign off paragraph suggested a meeting once I had had time to digest the report.

(2) A further covering letter dated 18 February 1999, sent to me by Ann Hithersay, Chief Executive of the Macfarlane Trust, referencing a typographical error in the copy of the Strategic Review previously provided and providing a corrected version **[DHSC0032142_010]**[2].

(3) A letter from Ann Hithersay to my diary secretary Joanne Willows, dated 13 May 1999 confirming that a meeting had been set up for 17 June 1999

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[2] I note that I sent an acknowledgement and holding reply to the Rev'd Tanner on 19 March 1999 in relation to the letters dated 29 January and 18 February **[WITN4505372]**

and enclosing a copy of the proposed agenda **[DHSC0003214_004]**[3]. This followed a letter that I had sent to the Rev'd Tanner on 13 April 1999 in which I confirmed that I had looked at the report in detail and invited him to contact Ms Willows to arrange a meeting **[DHSC0032142_005]**.

(4) A copy of the Strategic Review itself **[MACF0000045_019]**.

4.3. The Inquiry has also referred me to the following documents that were produced in connection with the meeting with the Macfarlane Trust:

(1) A minute to me from Gwen Skinner of the Health Service Division 1 (HSD1) dated 12 April 1999 **[DHSC0032142_007]**[4]. Ms Skinner apologised for the delay in providing advice on the invitation to meet the Trust. However, she advised in favour of a meeting. I note that under the heading 'The issue', Ms Skinner suggested as follows:

> *"2. The Macfarlane Trust operates the special payment scheme for people with haemophilia infected with HIV through NHS treatment with blood products. The Trust has reviewed its work after 10 years in operation. It makes a number of recommendations for Ministers/the Department, and for itself and the Haemophilia Society who have participated in the review and whose campaign in the 1980s prompted the establishment of the Trust. It asks for a meeting with Ministers to discuss the review's findings and we recommend acceptance.*
>
> *3. Essentially, the Trust recommends that it continues expenditure at about £2 million a year. This would require top ups to the Trust every two to three years of several million pounds to maintain its annual disbursement. Although there are fewer registrants with the Trust, their needs have changed and the items of expenditure are different. The main difficulty is that their financial support for HIV infected people with haemophilia might be considered over generous, eg help with house purchase and furnishings. There would also be a widening gap between this and the self help ethos which we are encouraging for those with hepatitis C."*

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[3] The proposed agenda, which is not included in the version provided by the Inquiry, has been located in DH records **[WITN5523002]**

[4] The Inquiry has also supplied me with what appears to be an undated draft of this minute from Ms Skinner **[DHSC0003222_005**].

Later in her minute, under the heading, 'Potential Difficulty', Ms Skinner said:

> *10. A potential difficulty is the focus which the report (perhaps unintentionally) brings to the balance between the relatively generous help for those who contracted HIV through blood products, and the absence of any special payment scheme for those infected with hepatitis C in the same way. This is especially noticeable in the case of young people, where those with HIV have help in setting up home, and those with hepatitis C have the Youth Information and Support project.*
>
> *11. The Haemophilia Society have been encouraged to promote the forward looking, positive thinking, self help route for those with hepatitis C. The exceptional circumstances leading to the past introduction of the HIV scheme have recently been requoted in a significant number of PQs – the widespread public fear of the disease at the time, when the infection was rapidly fatal and associated with sexual transmission. The HIV scheme has been justified on the basis of past circumstances, but in effect the difference today in the circumstances of a haemophiliac severely affected with hepatitis C and one infected with HIV is not so great."*

(2) A note of main recommendations being made to DH which would appear to have been extracted from the Strategic Review and a briefing note ahead of my meeting with the Macfarlane Trust [**DHSC0032142_003**].

(3) An undated draft letter from me to the Rev'd Alan Tanner **[DHSC0003232_007].** This appears to be a draft of the letter I sent on 1 July 1999, see paragraph 3.7, above.

(4) A minute dated 7 July 1999 from Charles Lister (HSD1) to Ms Adams (RMF-EAC2[5]) describing the outcome of the meeting on 17 June **[DHSC0006162_003].** Mr Lister recorded that I had agreed at the meeting to two aspects of funding for the Trust, explained in the following terms:

> *"• £52K in 1999 / 2000 to cover the cost of new IT equipment, software, staff retraining and year 2000 compliance. This is the request for funding I wrote to you about on 17 March and which was first raised by the Trust some 18 months ago. The money has already been spent by the Trust, and is mentioned in their 1998/99 accounts as an overspend against their management budget. The Trustees have taken the view that it is*

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[5] I am advised that this likely refers to the branch within the Resource Management & Finance Division which dealt with Finance for Central Public Health and other services (Civil Service Yearbook, 1999).

> *inappropriate to take this money out of the Trust Fund, a view supported by Lady Hayman. As there is no money through S64 for year 2000 compliance, we have told the Trust that the best we can hope for is to find the money out of any of-year underspend. I would be grateful therefore if you would flag this up as a potential call.*
>
> *• £2m in 2000/ 2001 to top up the Trust Fund. There is an ongoing commitment on the part of the Department to give periodic top-ups to the Trust Fund. Unfortunately, we did not realise when the BPRs were being written that a further sum would be needed in 2000/2001. By the end of this financial year, the Trust Fund is expected to be down to £5m or under. At least £4m of this is kept in capital investments in order to maintain payment levels, and grants from the fund currently total around £2m pa. It is therefore clear that a top up will be needed in 2000/2001, and the £2m suggested by the Trust seems reasonable. A further sum is likely to be needed in 2002/2003."*

My reflections on this are that I suspect that as a general principle I would not have wanted the Macfarlane Trust to fund their administrative costs with money that was supposed to go to beneficiaries, which is why the £52,000 amount has been separated from the two million top up.

(5) My letter to the Rev'd Tanner dated 1 July 1999 to which I have already referred at paragraph 3.7, above **[DHSC0006162_006].**

4.4. In addition to the documents provided to me by the Inquiry, I have seen the following documents from the DH records:

(1) An attendance note of a meeting held between the Macfarlane Trust and DH officials, Mike McGovern, Charles Lister and Gwen Skinner, on 14 June 1999. **[DHSC0003212_004]**

(2) An email dated 29 July 1999 from Charles Lister to Geoff Barrett in relation to the Macfarlane Trust's request for funding (i.e. £52,000) to cover the cost of new computer equipment **[DHSC0038637_043]**[6]. Mr Lister said that there was no money available to cover these costs at

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[6] I note that this email attaches the minute dated 7July 1999 from Charles Lister to Ms Adams, referred to at paragraph 4.3(4) above, and an unsigned undated version of my letter to the Rev'd Tanner of 1 July 1999, referred to at paragraph 3.7 above.

present, though the position would be reconsidered if there was any underspend at the end of the year.

(3) An email dated 11 February 2000 (after I had left the role of Parliamentary Under-Secretary of State for Health) from Charles Lister to Simon Jones, Gwen Skinner and Ann Willins. Mr Lister confirmed that the Macfarlane Trust could be reimbursed for the cost of upgrading their IT equipment through Section 64 (i.e. money could be transferred into the Section 64 budget in order for it to be paid to the Trust). **[DHSC0038637_004]**

(4) The Macfarlane Trust subsequently submitted a draft S64 application for this funding on 23 February 2000. **[WITN4505359]**

(5) A submission dated 25 February 2000 from Charles Lister to Lord Hunt seeking agreement to the award of a one-off Section 64 grant of £51,302 to the Macfarlane Trust **[WITN5523003].** I understand that the grant was subsequently authorised for payment on 13 March 2000 **[DHSC0033335].**

4.5. I am asked to comment on my understanding of what the Macfarlane Trust was asking of the government as a result of the Strategic Review. The Strategic Review identified that registrants of the Macfarlane Trust had longer life expectancies due to more effective HIV treatments and, in turn, had changing patterns of needs and expectations. It highlighted areas in which the Macfarlane Trust and related parties (i.e. DH) should adapt practices to accommodate such needs and expectations. The Macfarlane Trust's recommendations to DH were as follows:

> *"**Main Recommendations to the Department of Health/Ministers :***
>
> ***Consider changing patterns and increasing financial demands and expectancies of registrants - provide policy guidance and priorities; provide commensurate resources***
>
> ***Ensure ongoing funding to meet existing and emerging needs** (estimated by the Trust as a continuing £2 million pa) **and to continue to fund an efficient administration of the Trust***
>
> *This is the basic request for reassurance of continuing commitment to the Trust.*

> ***...***
>
> ***Other Recommendations to the Department/Ministers***
>
> *The Trust are likely to be content to discuss other items with officials.*
>
> ***To take measures to coordinate services and ready provision of information***
>
> ***To provide research funding for the monitoring of multiple drug therapies for haemophilia/HIV/hepatitis C, and information about adverse side effects be made available***
>
> ***To encourage effective partnership between Government Departments and statutory and voluntary organisations supporting people with haemophilia and HIV***
>
> ***To promote policies that deter all forms of discrimination based on HIV status***
>
> ***To ensure that Welfare Benefit Reviews include recognition of the nature of chronic illness with periods of respite typified by those with haemophilia and HIV***
>
> ***To ensure adequate funding is available to support Care in the Community for those who return home to be nursed when terminally ill***
>
> ***To ensure that adequate funding is available to enable Haemophilia centres to support psychosocial as well as medical needs of people with haemophilia and HIV.*" [DHSC0032142_003]**.

4.6. As I have mentioned already above, I cannot specifically recall my meeting with the Macfarlane Trust on 17 June 1999. However, having read the Strategic Review and briefing note for the meeting **[DHSC0032142_003],** I imagine that the Macfarlane Trust was looking for reassurance from me and DH officials that the government would continue to support the work of the Trust in light of the evolving needs of its registrants.

4.7. My letter to the Rev'd Tanner dated 1 July 1999 confirmed that I appreciated the need for the Macfarlane Trust (and related parties) to adapt working practices and expressed my full support for the Trust's work **[DHSC0006162_006]**. In particular, I committed to:

(1) Continuing the commitment to provide finances required by the Trust Fund.

(2) Continuing to fund the efficient administration of the Trust, including the costs of appropriate information technology.

(3) Considering the benefits issues raised by the Trust.

(4) Meeting with the Trust annually to "stocktake" any outstanding issues and offer assistance where possible.

4.8. My reading of the minutes of the trustee meeting held on 12 July 1999 (as set out at paragraph 3.8 above) leads me to conclude that the response was sufficient and had addressed what the Macfarlane Trust was asking.

Section 5: Relationship between the Macfarlane Trust and the Department of Health

5.1. I am asked for my view on the Macfarlane Trust's relationship with DH. In this regard, the Inquiry refers me to the following earlier correspondence, between the Rev'd Tanner and me from September 1998:

(1) The Rev'd Tanner's letter to me dated 30 July 1998 **[MACF0000174_040]**. This was sent to me only two days after my appointment as Parliamentary Under-Secretary of State for Health on 28 July 1998.[7] Having set out the background to the Macfarlane Trust, the Rev'd Tanner emphasised the falling mortality rates of those haemophiliac registrants infected with HIV and the particular impact of co-infection with Hepatitis C. He enclosed a copy of the interim Strategic Report and raised the issue of how the finalisation of the Strategic Review was to be funded. He said:

> *"You will see from the enclosed Interim Report that our Review is well underway, and that we are on target to present a Final Report to you in November. However, I am conscious that although your officials have agreed that we may use the £3,500 'underspend' from 1996/97, and despite the large amount of work that is being done 'in-house' by Trustees and staff, there will be considerable costs involved that cannot be met from our current Section 64 Grant.*
>
> *If we are to gain a true picture of the emerging needs of our Registrants, the work of conducting Focus Groups and One-to-One Interviews, as well as analysing the results of our detailed Questionnaire, must be carried out by professionals who are independent of the Trust and the Haemophilia Society. It would therefore be most helpful to know at this stage whether it would be possible for your Department to identify further funds to allow us to complete this important Review. The additional sum required is likely to be in the region of £15,000.*
>
> *I and my colleagues would welcome an early meeting with you if you would like to learn more about the Macfarlane Trust at this stage; however you may feel that it would be more appropriate for us to meet when we present our Final Report in the Autumn."*

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[7] I note that an acknowledgement and holding reply was sent on my behalf on 3 August 1998 **[DHSC0014990_082]**

(2) My letter of response dated 3 September 1998 **[MACF0000174_016]**. As I will address below, this letter followed advice and a draft from Christine Corrigan on 31 August. My reply included the following:

> *"I can understand why you would wish to employ professionals to help you with this work. This seems entirely sensible if the review is to be as objective as possible I am afraid, however, that we have been unable to identify any funds which might become available in-year which you could use to support this further work. Such funding would have to come out of Section 64 grant funds, which are already fully committed for this year.*
>
> *If you are unable to attract funding from any other source to progress the review, the only course I can suggest is for the Trust to put in an application for Section 64 project funding for 1999/2000. I appreciate that you might not wish to follow that path, as it would mean that completion of the review would be delayed, but that would seem to me to be the only alternative. You will of course be aware that Section 64 applications for 1999/2000 have already been invited, you will need, therefore, to submit the application quite quickly if that is what you intend to do.*
>
> *I am sorry that I cannot meet your request for additional funding in-year. I would, however, very much like to meet with the Trust to hear more about your work which I know is greatly valued by Registrants.*
>
> *Given the fundamental nature of the review, I think it would be best if, as you suggest, we wait until that study has been completed and we are in a position to discuss the Trust's future, as well as past, work. My Office will therefore be in touch to arrange a date as soon as we receive your final report."*

(3) The Rev'd Tanner's reply on 22 September 1998 **[MACF0000174_015]**. He wrote:

> *"Thank you for your letter dated 3rd September, and the thoughts you have expressed therein. I am particularly pleased to learn that the work of the Trust is valued, and that the Strategic Review we have commissioned has your support.*
>
> *In that respect the Trustees are of the view that it would be wrong for the Trust, being the creation and servant of the Government, to be seeking commercial sponsorship, particularly when the confidentiality of our work is paramount. It follows that we wish to pursue your suggestion that we put in an application for Section 64 project funding for 1999/2000, and although the relevant papers have only just been received from the Department we will deal with them expeditiously in the knowledge that your officials will exercise indulgence for late submission.*

> *This matter also highlights the fact that for reasons that appear to be beyond our control we have, at the same time and belatedly, received the papers enabling us to apply for a renewal of the Section 64 Core Grant for the next three financial years, which Grant is critical to secure the continuation of the administrative support for the Trust. For that reason this application, too, is going to be a late submission beyond the closing date of 18th September, but we have been assured by your officials that indulgence will again be exercised in this matter, and I therefore wish to assure you in return that it is receiving our immediate attention and the application will be lodged within the next few days.*
>
> *May I again thank you for writing, and for the encouragement you have given to the work of the Trust."*

5.2. In addition to the documents to which the Inquiry has alerted me, I note that:

(1) Ann Hithersay sent a letter to Christine Corrigan on 30 July 1998, enclosing copies of the Interim Strategic Report and letter from Rev'd Tanner to me of the same date. Ms Hithersay again raised the issue of how the finalisation of the Strategic Review was to be funded **[WITN5523004]**. She said:

> *"…it would be very helpful to have an indication of whether or not you think it likely that extra funds to complete the Review could be identified within the Department. Dr Mark Winter had heard that Dr Mike McGovern might have some money available for research, but what we are doing may not qualify because it is more orientated to 'psychosocial research' than purely medical research. It will be essential to identify some extra funding from some source very soon if we are to complete this important study.*"

I understand that the DHSC legal team has been unable to locate a response from Ms Corrigan to this letter. I assume that Ms Corrigan would have felt that there was no need for her to respond directly as my letter to Rev'd Tanner dated 3 September 1998 sufficiently addressed the matters raised.

(2) My letter of 3 September followed advice **[DHSC0014990_080]** and a draft response **[MACF0000174_016]** provided by Christine Corrigan on 31 August 1998. Ms Corrigan minuted my private secretary in the following terms:

> *"1. I am sorry that I was unable to meet your deadline for reply on this. I wanted to explore a couple of other possible funding sources, but these have not turned out fruitful.*
>
> *2. The letter from the Trust sets out the full background to the Trust's existence and the recent developments which led to the Strategic Review (which the Department in fact specifically asked the Macfarlane Trust to conduct, but which they were already contemplating). The Trust have now written requesting further funding to support the review and for a meeting with Baroness Hayman.*
>
> *3. I am a little surprised by the request for significant extra funding this late in the day, and also by the fact that Alan Tanner seems to imply that the review will be completed by the autumn, regardless of whether the Department provides that funding. Section 64 funds are already over-committed this year, not least because of a very late request from the Haemophilia Society for support (£50,000) for a project aimed at providing information and advice for young haemophiliacs with hepatitis C, which Secretary of State supported. There are a number of other organisations who have already bid for any further Section 64 funds which might become available due to slippage of other projects/spending, and I can see no grounds for claiming that this should take precedence over their claims. It might also be helpful for officials to have the opportunity to meet with the Trust to discuss the review in more depth before they go too much further. There are certain aspects of the preliminary findings which might be a cause for concern and which we would like to check out with them.*
>
> *4. In the light of all that, while Baroness Hayman should definitely agree to meet them, this would be better once we have the outcome of the review and their proposals for their future. We would therefore suggest delaying the meeting until then. A draft reply to that effect is attached."*

The draft letter provided by Ms Corrigan was adopted for the as-sent response dated 3 September.

(3) The Macfarlane Trust held a trustee meeting on 15 September 1998. The corresponding minutes **[MACF0000005_030]**, which I would not have seen at the time, read:

> *"The Chairman reported that he had received a response to his letter to Baroness Hayman that had accompanied the Strategic Review Interim Report which had been sent to her as the newly appointed Minister of State for Health at the end of July.*
>
> *Baroness Hayman had expressed interest in the Trust and its work and had welcomed the Review. However, she had said that the Department had been unable to identify funds available*

> *to support the work of the Review in the current year. She therefore suggested that an application be made for Section 64 Project funding for 1999/2000. Baroness Hayman also welcomed the opportunity of a future meeting with Trustees but felt that given the fundamental nature of the Review, a meeting should wait until the Review is complete and it would be possible to discuss the Trust's future, as well as past, work."*

(4) Ann Hithersay sent a letter to Charles Lister on 23 October 1998 in which she provided an update on the progress of the Strategic Review **[DHSC0003222_004].** I would not have seen this letter at the time, though I note that it helpfully sets out the funding position for the completion of the Strategic Review. Ms Hithersay wrote:

> *"...Baroness Hayman suggested that we apply for Project Funding under Section 64 in 1999/2000.*
>
> *However, since we had already committed to the Department our intention to deliver the Final Report in November, it was not possible to postpone the work already in hand.*
>
> *We applied for Section 64 Project Funding at the end of September, and allowed for additional work to feed back the results of the Review to the 480 living registrants and 31 'positive partners' in 1999/2000.*
>
> *....*
>
> *We plan to send the Final Report [to] the Department in early December.*
>
> *However, The Trust has already spent £7,558 on the Review and expects bills amounting a further £7,500 for work done facilitating Focus Groups and One-to-One Interviews and printing of the Final Report. Work to provide adequate feedback to Registrants would be an additional cost not included in the original budget, but written into our Section 64 Project application. We have received £3,553 from Section 64 underspend in 1996/97 referred to above, and so in the current financial year are looking at a projected overspend of approximately £11,505."*

(5) David Hewlett sent me and Dr Adam a minute dated 21 December 1998 entitled 'Section 64 General Scheme Grants 1999-2000: Submission from Branch HDD1' **[DHSC0006162_066]**. The submission sought my agreement to the 1999-2000 General Scheme expenditure plans for Branch HSD1, and included a recommendation to approve funding for the Macfarlane Trust to complete its Strategic Review. Mr Hewlett wrote:

> *"Renewed core grants to the Macfarlane and Eileen Trusts, and a project bid from the Macfarlane Trust are recommended. Both Trusts receive core grants for the costs of administering the special payment schemes established by Government to make special payments to those infected with HIV through treatment with blood or blood products.*
>
> *...*
>
> *In addition, the Macfarlane Trust has submitted a bid for a project grant to complete a strategic review of their work. They were invited to submit the bid by Lady Hayman, after a request for additional funds in 1998/99 could not be met within the S.64 budget. The strategic review has been prompted by a significant change in the death rate and consequent life expectancy of the remaining HIV registrants, following the introduction of new treatments. Those infected with HIV through blood or blood products are living longer, but have to deal with different, psycho-social problems, which may affect the way in which the Trust can best help.*
>
> *It would be publicly embarrassing if the administrative costs of the two Trusts were not to be covered. Equally, it would not seem sensitive to turn down the project application when some encouragement has been given, and when the project is a practical one designed to make the best use of the monies which the Trust receives and disburses."*

The Macfarlane Trust was notified on 14 June 1999 that the request for funding to complete its Strategic Review had been approved **[WITN4505371].**

5.3. In general terms, I do not have much recollection of the tone of the DH's relationship with the Macfarlane Trust. The letters from Alan Tanner I have referred to above all have a fairly positive tone to them as do the minutes from the Macfarlane Trust trustee meeting on 17 June 1999 (as set out at paragraph 3.6 above), and I have no reason to suspect that this is misleading.

5.4. The Inquiry invites my views on the Rev'd Tanner's statement that the Macfarlane Trust was "*the creation and servant of the Government*". I am also asked to confirm whether the Macfarlane Trust acted as the 'servant' of the government, or whether it operated at 'arm's length', or independently of the government. I do not have a recollection of what I thought at the time. However, having reviewed the documents, the governance of the Macfarlane Trust would not have struck me as particularly unusual.

5.5. I am asked whether DH had a view on whether it was appropriate for the Macfarlane Trust to seek funding other than from DH. Again, reflecting on this and knowing it was a charity, I imagine it would not have surprised me if the Macfarlane Trust received money from non-government sources.

5.6. Unless officials pressed the matter further, my letter of 3 September contained only a broad reference to the possibility of non-governmental funding ("*If you are unable to attract funding from any other source to progress the review …*"). Given that the allocated funding for the Strategic Review appeared to have been spent without achieving its completion, and with tight demands on S.64 funding, I do not consider that there was anything particularly unusual in my letter having at least raised the possibility of third-party funding.

5.7. I am asked whether there is a response to the letter sent by the Rev'd Tanner on 22 September 1998. I understand that neither the Inquiry, nor the DHSC legal team have been able to locate a response to this letter. After so many years, I am not able to assist further with whether or not a reply was in fact sent. I do observe that, reading the letter now, I would not particularly expect the letter to receive a response from a minister. The Rev'd Tanner does not ask for anything and on the whole seems content with my previous letter.

Section 6: Consideration of a special payment scheme for those suffering from Hepatitis C following treatment with blood or blood products

6.1. I am asked to comment on a decision made by Frank Dobson, Secretary of State for Health not to set up a special payment scheme for those suffering from Hepatitis C following treatment with blood or blood products. This decision was conveyed to the Haemophilia Society in a letter dated 28 July 1998 **[DHSC0016534]**. This letter was written on the same day that I was appointed as Parliamentary Under-Secretary of State for Health in the Lords. I did not, therefore, have any input into the decision. I expect that it would have involved both Baroness Jay as the responsible junior minister and Frank Dobson as Secretary of State[8]. While I was not involved in the decision communicated by Frank Dobson on 28 July 1998, the issue of a special payment scheme continued during my tenure as Parliamentary Under-Secretary of State for Health. I do however note that, as set out in my opening comments, I have very limited recollection of the events referred to by the Inquiry and, aside from my conversation with Mr Dobson on 28 July 1998, the remainder of this section is essentially a reconstruction of events based on the documents available to me and the reflections they stimulated.

6.2. I am asked by the Inquiry about the rationale for the decision and also whether I agreed with the decision. In that context, the Inquiry has referred me to a large number of documents and I set these out chronologically together with other relevant documents from the DH records:

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[8] I have seen from DH records a minute dated 24 February 1998 from Christine Corrigan to Fiona Anderson, Frank Dobson's private secretary, in which Christine enclosed a draft response to the Haemophilia Society. The draft letter conveys the decision not to set up a special payment scheme **[DHSC0003883_037 / WITN5523005]** though, for reasons not known to me, I note that the final letter sent to the Haemophilia Society on 26 February 1998 **[RHAL0000441_002]** does not. In any event, it indicates that the decision regarding the special payments scheme was being discussed well in advance of my appointment as Parliamentary Under-Secretary of State.

(1) A faxed collection of PQs dated 1987 in relation to the financial assistance given to haemophiliacs infected with HIV as a result of NHS treatment **[WITN5523006]**.

(2) A letter dated 24 June 1998 from Karin Pappenheim, Chief Executive of the Haemophilia Society to Baroness Ramsay, government whip, following the Lords' debate on 5 June 1998 **[HSOC0014188]**. This was about a month before I took up my post as Parliamentary Under-Secretary of State for Health in the Lords. The letter was copied to my predecessor Baroness Jay, Frank Dobson and Tony Blair. As well as taking up particular points from the debate, Ms Pappenheim pressed the case of extended financial support to haemophiliacs infected with HCV through blood products.

(3) Frank Dobson's answer to a PQ from Vernon Coaker on 28 July 1998 **[DHSC0006176_137**]. This was where Frank Dobson confirmed to the House his decision not to create an HCV payments scheme, as communicated to the Haemophilia Society in his letter that day.

(4) A letter dated 31 July 1998 from Chris Hodgson, chairman of the Haemophilia Society **[HSOC0013931]**, in response to Frank Dobson's letter dated 28 July 1998 (as referred to at paragraph 6.1 above). Members of the Haemophilia Society were, understandably, extremely disappointed by the decision not to grant financial assistance to those suffering from Hepatitis C following NHS treatment. It was Mr Hodgson's view that the circumstances of those infected with Hepatitis C were very similar to those infected with HIV and, therefore, that it was not justifiable to have a payment scheme in place for one group but not the other. Mr Dobson responded on 4 September 1998 to acknowledge the letter **[DHSC0041158_198]**. A copy of Mr Hodgson's letter is enclosed with Ms Pappenheim's letter dated 14 October 1998 to me ((7) below).

(5) The letter I sent to Karin Pappenheim on 21 August 1998 in reply to her earlier letter to Baroness Ramsay of 24 June 1998 **[HSOC0014266]**. I said as follows,

> *"You will by now have seen the Secretary of State's letter to the Society on this matter. I know that the Society will be deeply disappointed by our decision that it would be wrong to single out people with haemophilia infected with hepatitis C and to offer a financial scheme to this group as a special case. We have, however, reached that conclusion only after very serious deliberation.*
>
> *Frank Dobson's letter effectively dealt with the main issues in your letter of 24 June, but there are one or two further points I would like to make. I am surprised that you take issue with the general statement that haemophilia care has improved dramatically since the development of the relevant blood products. As Baroness Ramsay said, general life expectancy in the haemophilia community has increased considerably and we understand that the development of prophylactic care is helping many people, and youngsters in particular, to lead much more active and pain-free lives.*
>
> *Similarly, the latest treatments for hepatitis C must surely be welcomed. Although these are still in their very early days, indeed the anti-viral drugs are not yet licensed, these are showing quite remarkable results in studies so far. While the success rates of these drugs amongst people with haemophilia may not be as great, this may well improve with time, and each successful case is surely a step forward. We believe it is important to view these advances positively.*
>
> *The emergence of new variant CJD, on the other hand, is a very strong reminder that no matter what clinical advances are made, we cannot guarantee the absolute safety of any medical treatments. What we can do is make every effort to ensure that blood and blood products are as safe as we can reasonabl[y] make them."*

(6) A minute dated 25 September 1998 from Christine Corrigan to Frank Dobson to which I am copied, regarding an application by the Haemophilia Society for Section 64 funding for a project designed to support young people with haemophilia who had been infected with Hepatitis C through NHS treatment **[DHSC0041315_117 / WITN5523007]**. Ms Corrigan set out the benefits of supporting the project and sought a decision from Mr Dobson on whether to grant the funding. I can see that Fiona Anderson, Mr Dobson's private secretary, has annotated a copy of the minute as follows:

> "*This looks good – you wanted to give money to the Haemophilia Society – happy to agree? F"*

Mr Dobson subsequently agreed to fund the project[9]. I then wrote to Karin Pappenheim, Chief Executive of the Haemophilia Society, on 14 October 1998 to confirm that funding for the youth project had been agreed **[DHSC0041315_115]**. I wrote:

> "*Thank you for your letter of 26 May to Frank Dobson about the reduction in the Haemophilia Society's Section 64 funding this year. I am very sorry you have not received an earlier reply.*
>
> *I understand that since writing you have discussed this matter in some detail with Departmental officials and they have explained to you our policy of planning the emphasis in allocating such funding on innovative or forward looking projects which reflect the Government's objectives. Since then you have submitted a further application for funding for a project aimed at identifying and providing for the information and advice needs of young people with haemophilia infected with hepatitis C. I am pleased to hear that the project meets those criteria and that funding for the project has now been agreed.*"

(7) A letter dated 14 October 1998 from Karin Pappenheim in response to my letter of 21 August ((5) above), in which Ms Pappenheim expressed her disappointment in the government's decision not to set up a special payment scheme and sought a meeting with me to discuss issues relating to haemophilia care, blood products and the work of the Haemophilia Society more generally **[DHSC0041412_095]**.

(8) Hansard for 18 November 1998 containing John Hutton's written answer to a PQ from Dennis Skinner:

> *"We continue to hold the view that it would not be right to single out people with haemophilia infected with hepatitis C through National Health Service treatment by establishing a special payment scheme. Our general policy is that financial assistance of this kind is only paid where the NHS or individuals working in it, have been at fault."* **[WITN5523008]**.

(9) Advice from around 30 November 1998 to my Private Office, recommending in favour of my agreeing to a meeting with the Haemophilia Society **[DHSC0041408_106]**.

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[9] I can see that Mr Dobson wrote "Agreed" in response to Ms Anderson's annotation. Ms Anderson subsequently wrote to Ms Corrigan on 25 September 1998 to confirm that the grant should be given to support the project **[DHSC0041315_118].** Heather Rogers, another private secretary of Mr Dobson, once again confirmed to Ms Corrigan and Charles Lister on 28 September 1998 that funding for the project had been agreed **[WITN5523009].**

(10) A letter dated 1 December 1998 from Julia Gale, my diary secretary, to Karin Pappenheim **[DHSC0041408_107]**, in response to Ms Pappenheim's letter dated 14 October ((6) above). Ms Gale confirmed that I would welcome an opportunity to meet with the Haemophilia Society. I can see from the annotation on this letter that the meeting was scheduled for 21 January 1999.

(11) A minute dated 15 December 1998 from Joanne Willows, my diary secretary, to Charles Lister requesting a briefing ahead of my meeting with the Haemophilia Society on 21 January **[DHSC0041412_099]**.

(12) A minute dated 18 January 1999 from Gwen Skinner to me **[DHSC0041408_099]**, enclosing a briefing note ahead of my meeting with the Haemophilia Society on 21 January **[DHSC0041412_093]**. I cannot actually recall my meeting with the Haemophilia Society though understand from the briefing note that the items for discussion were as follows:

(a) The work of the Haemophilia Society,

(b) Recombinant Factor 8 & 9,

(c) The Society's Hepatitis C Youth Project, which we had recently granted funding for,

(d) Establishing the number of haemophiliacs with Hepatitis C,

(e) How haemophilia services fit into the government's agenda, and

(f) Compensation for haemophiliacs with Hepatitis C.

The briefing note also set out the points that it was suggested I raise at the meeting:

> *"pleased to have the opportunity to hear about the wide-ranging work of the Haemophilia Society;*
>
> *glad that we were able to ask Health Authorities and NHS Trusts to provide recombinant Factor VII from this year for all new haemophilia patients and children under age 16. We are now asking HAs and Trusts to provide recombinant Factor IX on the same basis when it becomes available shortly.*

> *we will shortly be making payments to Health Authorities for the extra costs of providing recombinant Factor VIII in the current financial year, as these were not planned for in advance. From next year onwards HAs will find the costs from their normal allocations. There will be no central funding for recombinant Factor IX this year as the costs will be comparatively low.*
>
> *glad that we were able to provide Section 64 funding for your hepatitis C Youth Project. Hope that it is progressing well.*
>
> *this Government wants to see an NHS which offers dependable high standards of care and treatment everywhere. That applies as much to haemophilia services as to any other. There are a range of initiatives set out in our White Paper – A First Class Service – which should have a positive impact on the services delivered by haemophiliacs.*
>
> *there is no likelihood of a National Service Framework for haemophilia – at least not for some time. There is only one new National Service Framework a year, and these have already been identified for two years in advance. Also at present, the NSF's have concentrated on widespread health problems such as mental health and coronary heart disease.*
>
> *it is not for the Department centrally to collect data on haemophiliacs with hepatitis C. However, we have funded the UK Haemophilia Centres Directors Organisation to review their data collection system. We trust this will include collecting data on infections, including hepatitis C.*
>
> *we have made a decision not to provide financial assistance to haemophiliacs with hepatitis C – and I believe that this was the right decision. We gave the issue very serious consideration and listened to all the arguments in favour of compensations, but concluded that it could not be justified."*

I understand that the DHSC legal team has been unable to locate a record of this meeting. I do, however, note that I referred to the meeting in a letter to Michael Mates MP on 2 February 1999 **[DHSC0041158_195]** in the following terms:

> *"Since you wrote I met with Chris Hodgson and the Chief Executive of the Haemophilia Society, Karin Pappenheim, on 21 January to*

> *discuss the issue of special payments as well as the other difficulties their members face. I assured them that the Haemophilia Society's presentation to Ministers last year was very moving and forceful and that the decision we took was very difficult. We recognise that hepatitis C may have some parallels with HIV infection but the introduction of the HIV special payment scheme in the 1980s was truly exceptional. The scheme reflected the fact that, at that time, HIV was a rapidly fatal new infection, the condition was marked by widely adverse public reaction and often hysteria, and all those infected, by whatever route, faced great stigma associated with the largely sexual nature of transmission. We recognise that infection with hepatitis C can cause great difficulty for people on top of their haemophilia and for their families, especially where more than one member is affected."*

(13) John Hutton's written answer to a PQ (1332) from Dafydd Wigley on 8 March 1999 **[DHSC0006176_048]**:

> *"As a general rule compensation or other financial assistance is only paid when the NHS, or individuals working in it, has been at fault. This is not the case with infection by HIV or hepatitis C through blood products before viral screening tests and inactivation processes were available. An exception to this general rule was the special payment scheme for people infected with HIV through NHS treatment with blood or blood products. This reflected the widespread public fear of the disease at the time, when the infection was rapidly fatal and associated with sexual transmission."*

Although I cannot recall doing so, I would expect to have seen and approved this response before it was signed off by John Hutton, as the subject fell within my portfolio as Parliamentary Under-Secretary of State for Health.

(14) Replies to PQs from Sir Geoffrey Johnson Smith in April 1999 which were for answer by John Hutton in the Commons but which were sent to me as well as John Hutton for approval **[WITN5523010]**.

(15) On 26 April 1999, I attended a meeting with the British Liver Trust where, amongst other things, issues concerning persons affected with HCV were discussed. The corresponding briefing notes that the British Liver Trust had launched an umbrella campaigning group for patients with HCV **[DHSC0003214_009]**.

(16) On 24 May 1999, I answered an oral PQ from Lord Morris:

> *"**Lord Morris of Manchester** asked Her Majesty's Government:*

> *What recent assessment they have made of the special needs of people with haemophilia who were infected with hepatitis C during NHS treatment, and the dependants of those for whom the infection proved fatal.*
>
> ***The Parliamentary Under-Secretary of State, Department of Health (Baroness Hayman):*** *My Lords, the Government made a thorough assessment in 1998 of whether it would be right to introduce a special payment scheme for people with haemophilia infected with hepatitis C through NHS treatment. We concluded that this would not be appropriate and that such patients should continue to obtain support as necessary through the benefits system in the same way as other NHS patients who have suffered non-negligent harm."* **[HSOC0023993]**

There were a number of supplementaries, the first from Lord Morris himself:

> *"**Lord Morris of Manchester:** My Lords, the Secretary of State for Health said last July that the social stigma of HIV and the danger of infecting partners were "important considerations" in granting special payments for HIV infection which do not apply in the hepatitis C cases. Can my noble friend point to where that was officially stated when the Major Government announced their HIV compensation scheme? Is my noble friend aware that governments elsewhere see no such distinction, and that Canada, Italy and Ireland already have special financial schemes for hepatitis C infection? How many NHS patients infected with hepatitis C have since died of liver disease? And when can we expect a response to the Haemophilia Society's urgent request for a public inquiry?*
>
> ***Baroness Hayman:*** *My Lords, I understand the strength of feeling. The campaign that the Haemophilia Society waged was moving and forceful. However, we concluded that a public inquiry was not the way forward and would not help prevention of future transmission. That has been covered by advances in screening and the ability to make blood products safer. I recognise the belief that there is a comparison with the HIV special payments. But there are also comparisons with large numbers of other patients who have suffered non-negligently as a result of treatment given as the best at the time. It is a difficult area but we do not believe that it would be appropriate to offer special compensation."*

(17) An undated, draft minute addressed to me that was intended to attach a draft letter to Lord Morris. It refers to a follow-up question (PQ 2447) from Lord Morris after my answer on 24 May 1999 **[DHSC0003216_006].** Lord Morris asked,

> *"…where it was officially stated that the social stigma of HIV, and the danger of infecting partners, were important considerations in*

> *the grant by the then Government of special payments to National Health Service patients infected with HIV during treatment."* **[DHSC0041305_145]**

(18) A minute dated 9 June 1999[10], sent from Gwen Skinner [HSD1] to Anita James and David Dunleavy, who I understand were both departmental legal advisers. The minute referred to my request for legal advice on the content of my response to PQ 2447 from Lord Morris and, in particular, Lord Morris's wish to see details of whether social stigma of the infected had featured in the government's rationale when announcing the HIV compensation scheme **[DHSC0003214_008]**.

(19) A letter dated 11 May 1999 from Lord Morris, on behalf of numerous MPs, to Tony Blair, then Prime Minister **[HSOC0014459]**. The Haemophilia Society had asked a number of MPs to request a meeting with Mr Blair to discuss their call for a public inquiry into the infection of the haemophilia patient group with HIV and hepatitis blood viruses as a result of NHS treatment. This letter was forwarded to Frank Dobson's private secretary, Heather Rogers, for comment on 17 May 1999 **[WITN5523011]**.

(20) What I understand to be detailed speaking notes for me in relation to an oral answer to Lord Morris's PQ 2032 **[WITN5523012]**. Lord Morris asked:

> *"…what recent assessment they have made of the special needs of people with haemophilia, who were infected with hepatitis C during NHS treatment, and the dependants of those for whom the infection proved fatal."*

I responded:

> *"We made a thorough assessment in 1998 of whether it would be right to introduce a special payment scheme for people with haemophilia infected with hepatitis C through NHS treatment. We concluded that this would not be appropriate and that such patients should continue to obtain support as necessary through the benefits system in the same way as other NHS patients who have suffered non negligent harm."*

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[10] On its face, the minute is dated 9 May 1999 but this is clearly an error as it is referring to the answer already given on 24 May 1991

The speaking notes included a section entitled, *'Reasons for a special payment scheme for HIV but not Hepatitis C',* which stated*:*

> *"The special payment scheme for those infected with HIV (Human Immunodeficiency Virus) was introduced in 1988. At that time there were very strong public attitudes to HIV – of stigma, and widespread fear of a new and untreatable fatal infection which was sexually transmitted. The payment scheme has continued since then.*
>
> *The same circumstances do not apply to hepatitis C. We accept that those infected in this way do face difficulties, as do other NHS patients and groups of people who unfortunately suffered unforeseen harm which could not have been avoided. We aim to support those with haemophilia infected with hepatitis C through the benefits system, where appropriate, and through a number of projects which we support through the Haemophilia Society."*

They also contained information regarding DH's default position in respect of other injuries / infections caused by NHS treatment, i.e. that compensation would only be paid when legal liability could be established.

(21) Further legal advice dated 9 June 1999 from David Dunleavy to Gwen Skinner regarding PQ 2447 and the decision in 1987 to set up a special payment scheme for haemophiliacs infected with HIV as a result of NHS treatment **[DHSC0016531]**. Ms Skinner emailed Trish Fretten the same day referring to this advice and considering how it would inform my response to PQ 2447 **[DHSC0003214_002]**.

(22) Minute dated 10 June 1999 from M Wilson to David Dunleavy [**WITN5523013]**. It reads:

> *"As a meeting today with Lady Hayman about compensation for the Radiotherapy Action Group women, she mentioned a PQ about there being no compensation scheme for Hep C cases. She mentioned she would like SOL to look at the answer again. David and Anita appear to have been involved. From what I gather PS(L) is not persuaded that there is much difference between the HIV cases and the Hep C cases. I think she's looking for more info for setting up the HIV scheme. Trish is PS(L)'s Office can give more details."*

(23) Email dated 11 June 1999 from David Dunleavy to Trish Fretten and Gwen Skinner concerning the decision to offer a special payment scheme to haemophiliacs infected with HIV through NHS treatment, and

the difference between this and the decision regarding haemophiliacs infected with Hepatitis C **[DHSC0041341_244]**. He wrote,

> *"I am told that that John Canavan was the administrator who dealt with the HIV scheme (I believe that were two schemes- one for haemophiliacs and one for others) and that he is still around. Also, I am told that Roger Moore and Charles Dobson were involved. Speaking to them might be the best way to get the true picture of the situation.*
>
> *Perhaps it was the case that we thought we were on weak legal ground in the HIV case and we feel on safer legal ground now (or at least haven't been pushed that far yet – I just don't know and we in solc2 don't have any papers). I believe that solb4 have huge litigation files relating to HIV but they might not deal with what was said publicly.*
>
> *When it comes down to what was or may have been said publicly I suspect that it is difficult to find any difference in the merits of the groups themselves ie between then and now."*

(24) Email dated 11 June 1999 from Gwen Skinner to Trish Fretten **[DHSC0041341_245]**, which reads:

> *"There seem to be a lot of messages which are a bit confusing on hepC/HIV. On the background to the HIV scheme, I have the files, includingb PO cases etc. If you let me know what Lady Hayman wants, I will look it up. I am interviewing this morning."*

(25) Email dated 11 June 1999 from David Dunleavy to Trish Fretten and Gwen Skinner **[DHSC0016528]**. He wrote:

> *"Further to my e-mail of earlier today I gather that work was done by Keith Young (in relation to CJD) as to the arguments for a special payment scheme in the case of HIV and why that case could be said to be different from the CJD case. It sounds as if he should be able to help."*

(26) Note on financial help for haemophiliacs infected with Hepatitis C virus through treatment products **[WITN5523014]**.

(27) Hansard for 15 June 1999 containing my written answer to Lord Morris's PQ 2447:

> *"My right honourable friend the Secretary of State for Health gave the view of this Government when he wrote to the Haemophilia Society on 28 July 1998. He said, with regard to the decision not to introduce a special payment scheme for people with haemophilia infected with hepatitis C through National Health Service treatment, that the circumstances of the people infected with HIV were different. He added that the stigma surrounding HIV at the time the*

> *decision was taken, the fact that it was generally considered a sexually transmitted disease and that haemophiliacs could have inadvertently infected their partners were all important considerations which do not apply to hepatitis C."* **[DHSC0041305_145]**

(28) Suggested replies to PQs 2608, 2609 and 2610 from Lord Morris in June 1999 regarding the social stigma of being infected with Hepatitis C **[WITN5523015]**.

(29) A further draft response to PQ 2608 from Lord Morris **[DHSC0041341_199]** in which I have attached a handwritten note that reads:

> *"Again, I would be grateful if Simon Stevens could look at this before I sign off."*

Mr Stevens was at that stage Special Adviser to the Secretary of State for Health. Given that the decision not to introduce a special payment scheme for people infected with Hepatitis C was a sensitive topic, I imagine I would have wanted to be certain that the Secretary of State's office was content with the response.

(30) Fax from Gwen Skinner to my Private Office in June 1999 enclosing a letter dated 1 June 1998 from Baroness Jay to Frank Dobson regarding ex-gratia payments to haemophiliacs infected with Hepatitis C **[WITN5523016]**.

(31) Hansard for 28 June 1999 containing my written answer to a PQ from Lord Morris:

> *"When we made our careful assessment of the request for a special payment scheme for people with haemophilia infected with hepatitis C we took account of the very high level of stigma attaching to HIV in the 1980s when the HIV special payments were introduced"* **[WITN5523017]**.

(32) Letter to me from Lord Morris dated 29 June 1999 **[DHSC0041305_141]**. Lord Morris referred to my reply of 15 June and forwarded a letter from Ms Pappenheim. He also provided me with a copy of a further PQ he was tabling. The enclosed letter from Ms Pappenheim was dated 23 June 1999 [**HSOC0014604]**. She took issue with the answer that I gave in response to PQ 2447 from Lord Morris in that it did not represent an

accurate explanation of the government's decision in 1987 to introduce a special payments scheme for people with haemophilia infected with HIV via contaminated blood. While I had responded on the basis that the 1987 government considered the stigma surrounding HIV at the time, Ms Pappenheim felt that the decision was more to do with the pressure of litigation, the profile of HIV in the media and the all-party pressure. Ms Pappenheim's letter was also forwarded by Lord Morris to Tony Blair on 1 July 1999, which was then passed on to Heather Rogers, Frank Dobson's private secretary, for comment **[WITN5523018] [WITN5523019]**. The letter dated 29 June 1999 contains a handwritten annotation from me which states:

> *"+ pl copy Simon into all this correspondence."*

As at (29) above, I understand this to be a reference to Simon Stevens, then Special Adviser to the Secretary of State for Health.

(33) Letter to Lord Morris from Karin Pappenheim dated 29 June 1999 [**HSOC0014601]** in which she expressed disappointment at the recent letter from Tony Blair in which he had turned down a request for a meeting and rejected calls for a public inquiry.

(34) Minute to me from Charles Lister with a draft substantive reply to Lord Morris' letter of 29 June 1999 **[WITN4505005 / WITN5523020]**.

(35) A handwritten note which appears to be dated 2 July 1999 and is addressed to me **[WITN5523006]**. I understand that the note relates to two proposed replies to PQ 2839 from Lord Morris [**WITN5523021]**. It reads:

> *"Lady Hayman*
>
> *Officials have prepared alternative replies to this PQ – suggesting as last sentence denotes, whether you may wish to write to Lord Morris with a more detailed response to the points made by the Haemophilia Society. Can you please sign on reply you prefer."*

(36) Hansard for 5 July 1999 containing my written answer to PQ 2839 from Lord Morris. Lord Morris asked:

> *"What representations they have received from the Haemophilia Society concerning the Written Answer given by the Baroness Hayman on 15 June (WA 18) about the distinction made between people with haemophilia infected with HIV and hepatitis C respectively during NHS treatment; and what action they are taking in response to these representations"*

I responded:

> *"We have received a letter from the Haemophilia Society on this issue. However, the representations made by the society have not convinced the Government to alter their decision that haemophiliacs infected with hepatitis C through National Health Service treatment should not receive special payments. I will write to my noble friend addressing the specific points made by the Haemophilia Society."* **[WITN5523022]**

(37) A minute dated 16 July 1999 from Gwen Skinner (HSD1) to Dr McGovern, Charles Lister and Ann Willins, addressing the issue of the distinction between HIV and HCV infection for haemophiliacs **[WITN4505006]**. Ms Skinner wrote,

> *"In the 1980s, when the HIV decision was made, HIV was rapidly fatal. Hep C is not. The difference between HIV and all the other "harm" circumstances of a range of groups is that HIV meant imminent death. All the others mean impairment of quality of life. The key thing – life - is still present and the challenge is to devise means of overcoming the new difficulties.*
>
> *It is difficult that the 1987 statements attribute the HIV decision to the fact of another serious disease superimposed on the pre existing haemophilia. I have spoken informally to Roger Moore who was the G7 at the time. He said that the decision to introduce the scheme was an emotional one, made on the spur of the moment after a moving presentation to the then SofS by two young haemophiliacs. Before that moment there had been no intention whatsoever to agree to a scheme. RM described the decision as irrational."*

This email was not copied to my Private Office. However, from the email train, Ms Skinner's comments appear to follow an email from Dr Adam suggesting that I was "fretting" about the distinction between HIV and HCV infection of haemophiliacs and had sought Dr Adam's views **[WITN4505006]**.

(38) A email also dated 16 July 1999 from Charles Lister to Dr Adam, in which Mr Lister provided an amendment to the submission that Dr Adam was preparing to send to me **[DHSC0041305_128]**[11].

(39) A submission dated 21 July 1999, sent to me by Dr Adam, entitled "*Haemophilia and HCV*" **[DHSC0041305_123]**. From the face of the submission, and consistent with the above, it is clear that I had asked for further briefing on the distinction being made between HIV and HCV infection of haemophiliacs. Dr Adam wrote:

> *"… When we spoke, you were clear that there is no easy solution here, and I can only agree with that. We have made a distinction between haemophilia and HIV and HCV, and this is difficult to explain logically.*
>
> *2. As we discussed, the decision about HIV and haemophilia is undoubtedly tied up with contemporary feelings about HIV in 1987 - when HIV was a rapidly fatal disease. I can remember the emotional impact of our realisation that, through their medical treatment, we had transmitted this inevitably fatal disease to a group of often young people who already had a serious and disabling condition.*
>
> *3. The distinction is not of course only between HIV and HCV in haemophilia. We have also made a distinction between on the one hand haemophilia and HIV, and on the other a number of examples of the NHS inadvertently harming people - the examples you quoted were myodil and radiotherapy for breast cancer. Human growth hormone is another one, as are the rare examples of vaccine damage. Any shift in our position on haemophilia and HCV would therefore have far reaching consequences.*
>
> *4. A further complication is that the NHS Litigation Authority are urging an out-of-court settlement in the group action being brought against the NBA by blood recipients infected with HCV between 1988 and 1991. A submission will be coming to you on this in the next few days.*
>
> *5. If you would find it helpful, Charles Lister, Mike McGovern and I would be happy to meet you to talk through these issues in greater detail. It might be best to do this when you also have the submission referred to in Para 4.*
>
> *6. Meanwhile, I have not modified the draft letter to Lord Morris and will return the papers to your office. Please let either Charles Lister or me know if you would like us to have another go at the letter."*

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[11] The document provided by the Inquiry appears to be incomplete and theDHSC legal team has been unable to locate a complete copy of this document in DH records.

(40) An email from my APS (Lee McGill) to Dr Adam conveying my wish to take up the offer of a meeting with officials to discuss the question of haemophiliacs with HCV **[DHSC0041305_121]**. This also noted that I had asked that Dr Adam's submission of 16 July be forwarded to Simon Stevens.

(41) A minute dated 23 July 1999, from Charles Lister to the Private Office of Tessa Jowell; this was copied to the Secretary of State's Private Office and to mine **[DHSC0014990_029]**. The minute advised against agreeing to a meeting between the Manor House Group and the Secretary of State but in favour of my meeting them as the minister responsible for the area. It was noted that the Manor House Group favoured more direct action than the Haemophilia Society and would be lobbying for financial assistance. The minute noted that I was due to meet officials 'shortly' to discuss the issue of haemophiliacs with Hepatitis C and it was suggested that my meeting with the Group should take place once that meeting with officials had taken place.

(42) A letter dated 26 July 1999 that I sent to Yvette Cooper MP, explaining – in the context of a question from one of her constituents – the government's decision not to create a special payment scheme for people with haemophilia **[DHSC0041158_007]**.

(43) Throughout my tenure, my Private Office dealt with a significant amount of correspondence with MPs relating to the decision not to introduce a special payment scheme for haemophiliacs infected with Hepatitis C through NHS treatment. Ordinarily, draft responses would be prepared by officials within my Private Office and passed onto me for approval and signature. To the extent possible, it was my preference for responses to be personalised and I would ask for any letters that I was not happy with to be amended before sending. By way of example, I have seen the following documents from the DH records:

(a) A letter dated 15 September 1998 to Marion Roe MP regarding a letter she had received from the Haemophilia Society **[WITN5523023]**;

(b) A letter dated 1 October 1998 to Caroline Spelman MP regarding her constituent, Mr GRO-A **[WITN5523024]**;

(c) A letter dated 12 October 1998 to Valerie Davey MP regarding her constituent, Dr GRO-A **[DHSC0046034_067]**;

(d) A letter dated 7 December 1998 to Geoffrey Clifton-Brown MP regarding a letter he had received from the Haemophilia Society **[DHSC0041315_163]**; and

(e) A letter dated 11 February 1999 to Nick Ainger MP **[DHSC0041158_167]**.

Documents post-dating my move to be Minister of State, MAFF:

(44) Letter dated 11 August 1999 from Chris Hodgson to Lord Hunt **[HSOC0014593]**.

(45) Briefing for Lord Hunt ahead of a meeting with officials on 7 September **[DHSC0041304_045]** (covering note) and **[SCGV0000169_007]** (briefing for meeting). I infer that this may have been the meeting with officials on the rationale for decisions regarding financial support for haemophiliacs infected with Hepatitis C that I had requested but which had not taken place before my move to MAFF.

(46) Briefing prepared for Lord Hunt, my successor as Parliamentary Under-Secretary of State, for his oral response to a PQ from Lord Morris's to be heard on 18 December 2000 **[DHSC0006168_095]**.

6.3. I am asked by the Inquiry about the rationale for the decision not to set up a special payment scheme for those suffering from Hepatitis C following treatment with blood or blood products, and also whether I agree with the decision. I wish to emphasise that I have relied heavily on the documents available to me in preparing my response. Writing this statement has required me to piece together how I felt at the time and, as set out in my opening comments, it is more of a reconstruction than an actual recollection.

6.4. With that in mind, having reviewed the material provided by the Inquiry and the DHSC legal team, I clearly felt uneasy about the decision not to introduce a special payment scheme for haemophiliacs infected with Hepatitis C through NHS treatment. In particular, the email dated 21 July 1999 from Dr Adam (as described at paragraph 6.2(39) above) refers to me "*fretting*" about it. This was an email sent between DH officials so I would not have seen it at the time but I was undoubtedly concerned about the decision that had been made and was trying to work out in my own mind whether the right balance had been struck.

6.5. As noted above, I became Parliamentary Under-Secretary of State for Health in the Lords on 28 July 1998, the same day that Frank Dobson confirmed in the House of Commons the government's decision not to establish a financial scheme for those infected with Hepatitis C via blood or blood products. I cannot speak directly to the reasoning behind that decision or the advice that he and my predecessors had received on the matter. However, Mr Dobson was a caring and generous man and I know that this decision would have weighed heavily on him and would not have been taken lightly.

6.6. Prior to the ministerial reshuffle when I became Parliamentary Under-Secretary of State for Health, I believe that the plan was for my predecessor, Baroness Jay, to announce that there would be no financial scheme for those who had been infected with Hepatitis C. Mr Dobson, being who he was, felt that it was unfair to ask me to take ownership for a decision to which I had not been party and in respect of which I was not fully aware of the background and rationale. It was for this reason that he, rather than I, made the announcement on 28 July 1998.

6.7. I cannot recall what I thought of the decision at the time. At that point I knew little of the background and imagine I would have accepted that this was a very recent policy decision for which I would have to take collective responsibility.

6.8. I have touched on this above in relation to the Inquiry's question regarding the briefing of junior ministers but it was not unusual for ministers to enter a new role without a formal briefing and/or handover. Any briefing at the time would, I think, have concentrated on decisions which were needed in the immediate future rather than on issues which had, by then, been settled.

6.9. The documents presented to me indicate that I became increasingly concerned about the decision in relation to Hepatitis C patients during my time at DH. Lord Morris was a key part of this. He was a much respected figure in the Labour party and had a lot of support in the Lords, especially on health matters. His advocacy on behalf of those who had been infected with Hepatitis C was compelling. The PQs that he raised throughout my time with DH prompted me to think very carefully about this topic, and I took pains to make sure that my answers were accurate and reflected the government's position correctly, hence my requests for legal advice at several points.

6.10. Clearly, it was an extremely difficult subject. On the one hand, HIV patients had exceptional needs when the Macfarlane Trust had been set up because of the often fatal impact of HIV/AIDS. However, by 1999 advances in treatment meant that it was more difficult to justify the difference in treatment of the two groups. I imagine I struggled with the existing policy that these two groups of people should be treated differently, given that they had received the same treatment with comparative levels of severe consequences.

6.11. On the other hand, it was clearly an established principle that the NHS does not pay no-fault compensation and, if there was one exception, there would be many more sought. I had previous experience with the general topic of no-fault compensation. I had been the chair of the Whittington Hospital NHS Trust and NHS Litigation was part of my portfolio in DH so this was not a theoretical concern. Hepatitis C patients were not the only group of patients in a similar position that I had encountered that year. For example, I was aware of women who had suffered as a result of radiotherapy in the course of treatment for breast cancer. I was aware that we could set precedents in this area that might have a huge impact on the finances of the Health Service and of the patient care it could deliver.

6.12. Towards the end of my time at DH, I was clearly troubled, attempting to clarify the position I should take and wanting to explore whether there was any way of providing financial support for Hepatitis C patients without creating a general no fault compensation scheme by default.

Section 7: Other Issues

7.1. I am asked for any other information or views I have that may be relevant to the Inquiry's Terms of Reference. I do not believe that I have anything to add beyond that set out above.

Statement of Truth

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

Signed..... GRO-C ....

Dated........ 12 · IX · 2022 ....