Witness Name: John Rhodes Horam
Statement No.: WITN5294001
Exhibits: WITN5294002 - WITN5294018
Dated: 13/05/2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LORD JOHN HORAM

Contents

I, John Rhodes Horam, will say as follows: -

Section 0. OPENING COMMENTS

0.1. My name is John Rhodes Horam (Lord Horam). I was Parliamentary Under Secretary of State for Health in the House of Commons between 29 November 1995 and 1 May 1997. I was made a life peer in 2013 and I am an active member of the House of Lords. I provide this statement to the Inquiry in response to a Rule 9 request dated 11 February 2022, as amended by a further request dated 21 February 2022. My date of birth and address are known to the Inquiry.

0.2. I have followed the section headings in the Inquiry's request and where sensible to do so I have grouped my answers under the same subjects.

0.3. I have deep sympathy for the suffering of those impacted by the subject of this Inquiry and I hope the information contained in this statement goes, in some way, to assist the Inquiry in piecing together the overall picture and provide answers to those infected and affected.

0.4. Throughout my political career, of which I set out my various roles more particularly in Section 1, I have sought to understand the issues impacting on any given problem and to fully explore the options available before taking decisions or making recommendations.

0.5. I was Parliamentary Under Secretary of State for Health for a period of 17 months between 29 November 1995 and 2 May 1997.

0.6. I took up the role as Parliamentary Under-Secretary of State for Health as part of a minor re-shuffle of junior Ministers. I cannot recall receiving any particular handover or briefing from my predecessor, Tom Sackville. Rather, my officials briefed me on relevant issues as and when they first arose during my tenure.

0.7. As I suspect is the case for many of the other witnesses, given that the events relevant to the Inquiry took place over 25 yours ago, I have limited independent memory of that time. I have been assisted by the documents provided by the Inquiry and those made available to me by the Department of Health, now the Department of Health and Social Care ("the Department"). Some of the documents have triggered independent memories but for the most part I have relied on the content of the documents available to me in order to reconstruct the events and matters discussed in my witness statement.

Section 1: INTRODUCTION

1.1. I am asked about my professional qualifications and the roles I have held throughout my career; including any roles in committees, working parties or groups etc relevant to the terms of reference.

1.2. My academic background and professional career outside of politics have been in the economics and business spheres. I did not therefore bring any medical or scientific qualifications or expertise to the role of Parliamentary Under Secretary for Health.

1.3. My first post graduate job was in market research for Rowntree & Co between 1960 – 1962. I then worked as a journalist for the Financial Times between 1962 – 1964 and for the Economist between 1965 – 1968.

1.4. I was the Managing Director of Commodities Research Unit Limited, now CRU International Limited, between 1968 – 1970. The company is a privately-owned business intelligence company, focusing on the global mining, metals and fertilizers markets. It provides consultancy, market analysis, business analysis, news, data and conferences services. I returned as Managing Director between 1983 – 1992 and I am currently a Non-Executive Director.

1.5. I was first elected to parliament in June 1970 as MP for Gateshead West. I held this seat until 9 June 1983, first as a Labour MP and then, from 2 March 1981 as a member of the Social Democratic Party.

1.6. I did not gain re-election in the 1983 election and returned to work for CRU.

1.7. I had a break from Parliamentary politics, but joined the Conservative Party in 1987. I then won the Orpington parliamentary seat for the Conservatives in the

April 1992 election. I held that seat until 6 May 2010, whereupon I stepped down.

1.8. I was created a life peer in 2013.

1.9. I had the following appointments in government (in bold) and roles in opposition;

(a) **12 September 1976 – 3 May 1979: Parliamentary Under Secretary of State, Department of Transport** (Labour Government);

(b) 1979 – 1981: Labour opposition spokesman on economic affairs;

(c) 1981 – 1983: SDP opposition spokesman on economic affairs;

(d) **6 March 1995 - 27 November 1995: Parliamentary Under Secretary of State, Office of Public Service and Science (OPSS), Duchy of Lancaster Office** (Conservative Government);

(e) **29 November 1995 - 1 May 1997**: **Parliamentary Under Secretary of State, Department of Health** (Conservative Government).

1.10. My parliamentary committee memberships include:

(a) 27 April 1992 - 31 March 1995: Public Accounts Committee.

(b) 12 November 1997 - 16 July 2003: Environmental Audit Committee, Chairman.

(c) 2 December 1997 - 16 July 2003: Liaison Committee (Commons).

(d) 12 July 2005 - 6 May 2010: Foreign Affairs Committee.

(e) 27 November 2013 - 14 May 2014: Delegated Powers and Regulatory Reform Committee.

(f) 12 June 2014 - 30 March 2015: Communications and Digital Committee.

(g) 12 June 2015 - 2 July 2019: EU External Affairs Sub-Committee.

(h) 5 March 2020 – 2021: High Speed Rail (West Midlands - Crewe) Bill Select Committee (Lords).

1.11. I doubt that my other outside interests or appointments are relevant to the Inquiry but for completeness:

(1) I was a Commissioner at the Electoral Commission from 2011 – 2018.

(2) I was the first chairman of the Circle 33 Housing Trust, which is now known as Clarion Housing.

(3) I was Chairman of the St Catharine's Society, Cambridge from 2005 – 2013 and its President between 2014 – 2015. I was elected a Fellow Commoner of St Catharine's College in 2010.

Responsibilities as Parliamentary Under Secretary of State for Health

1.12. I have been asked to describe my role as Parliamentary Under Secretary of State for Health in so far as they are relevant to the Inquiry's Terms of Reference.

1.13. As was usual for the Department at that time, ministerial responsibilities were shared between the three Parliamentary Under Secretaries of State for Health. At that time, John Bowis was the other Parliamentary Under Secretary for Health in the House of Commons, who was then replaced by Simon Burns on 23 July 1996. In the Departmental documents John and then Simon were referred to as PS(C) and I was PS(H). Baroness Julia Cumberlege was the Parliamentary Under Secretary of State in the House of Lords (PS(L)). Stephen Dorrell was the Secretary of State for Health and Gerald Malone the Minister of State for Health throughout my tenure.

1.14. I can see from the Department's press release[1], dated 29 November 1992, which announced my appointment that my remit was wide ranging. The press release sets out the 31 areas of responsibility and included the following notable areas:

(a) Acute services (including cancer);

(b) National Blood Services;

(c) Private Finance Initiative;

(d) Capital investment;

(e) Department of Health management (including DoH agencies);

(f) Waiting lists;

(g) Community Health Councils;

(h) Family planning; and

(i) NHS Estates.

1.15. I recall that during my 17 months as Parliamentary under Secretary of State for Health the majority of my time was spent dealing with two large pieces of work; those being the Private Finance Initiative ("PFI") and the reorganisation of the Community Health Councils.

1.16. PFI, which was a policy designed to increase private sector involvement in the provision of public services, took up a substantial amount of my time. It involved extensive discussions with Treasury and Department officials, particularly around the allocation of risk between the private providers and the public sector.

1.17. The reorganisation of the Community Health Councils took even more time because I had to put a bill through Parliament.[2] Taking bills through parliament,

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[1] This was exhibited to my BSE evidence as is retained in that Inquiry's publicly available records at https://webarchive.nationalarchives.gov.uk/ukgwa/20060525120000/http://www.bseinquiry.gov.uk/evidence/index.htm

[2] The Community Health Councils Regulations 1996 which came into force 1 April 1996.

I recall, was like entering a tunnel, it took nearly all of your time until you emerged at the other end.

1.18. In addition to those responsibilities listed in the press release, from 31 January 1996, I took over responsibility for BSE and CJD from Baroness Cumberlege.

1.19. I can see from the available documents that Baroness Cumberlege held and retained general responsibility for treatment and matters pertaining to HIV and Hepatitis C.[3]

1.20. I had responsibility for National Blood Services and the issue of those infected as a result of infected blood and blood products. My portfolio included a responsibility for policy on any additional help and treatment given to those infected. This would have included the lookback exercise that was being undertaken to identify those infected with hepatitis C through blood or blood products **[DHSC0004469_013]**.

1.21. From the papers I have seen John Bowis had responsibility for dealing internationally with blood issues. He would lead on any meetings with colleagues in the Department of Health in Ireland **[DHSC0006856_006]**; **[DHSC0006856_007]**; **[DHSC0006856_008]**; **[WITN5294002]**; **[WITN5294003]**.

1.22. Any new, or significant changes of, Departmental policy would be agreed by the Secretary of State for Health. There were regular Ministerial meetings. Submissions to one Minister would often be copied to the Private Secretaries to the other Ministers. My private secretary would have exercised discretion in

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[3] See for example: 27 November 1995 letter from Baroness Cumberlege regarding World AIDS day **[DHSC0014958_075]**; letter from Baroness Cumberlege to David Congdon MP, 17 March 1996 re Alpha interferon treatment; [**DHSC0042289_198**].

deciding whether documents addressed primarily to other Ministers should be included in my own boxes for me to note.

1.23. Whilst my time at the Department was limited and health policy was a new area of interest for me, I was pleased to be able to tackle such an interesting and important topic.

Evidence to other inquiries, investigations or criminal or civil litigation

1.24. I have not given previous evidence or been involved in previous inquiries, investigations, criminal or civil litigation in relation to the human immunodeficiency virus ("HIV"), hepatitis B virus or hepatitis C virus infections in blood or blood products. In respect of variant Creutzfeldt-Jakob disease ("vCJD"), I gave two written statements to the BSE Inquiry in relation to my time as Parliamentary Under Secretary of State for Health. I exhibit at **[WITN5294004]** and **[WITN5294005]** copies of those statements. I was not called to give oral evidence.

Section 2: ALLIANCE HOUSE ORGANISATIONS AND HEPATITIS C ISSUES

General

2.1. I have been asked whether I received a briefing, on taking office, about the Alliance House Organisations ("AHOs"). I have also been asked to describe any briefing I received about the circumstances and needs of the beneficiary communities served by the AHOs and/or more generally the circumstances and needs more broadly of those who had been infected with HIV or hepatitis as a result of their treatment with blood or blood products.

2.2. As I described at paragraph 0.6 above, the reshuffle which resulted in my appointment as Parliamentary Under Secretary of State for Health was a limited one. There would not, I think, have been any internal planning for a change of Ministers. I cannot recall receiving any briefing immediately upon taking office in relation to the AHOs or those who had been infected with HIV or hepatitis as a result of their treatment with blood or blood products. I expect I would have had some introductory meetings with key senior officials early on but these would not have descended into detail on individual policy areas. I think it more likely that my officials would have briefed me and brought me up to speed when a policy issue first arose in each of my portfolio areas. I trusted that my officials would bring matters to my attention and provide such briefing, with the requisite detail, as they judged appropriate in order for me to make an informed decision or to be sufficiently prepared for any meeting or Parliamentary Question ("PQ").

2.3. From my review of available papers, I can also see that the Haemophilia Society's 'Hepatitis C Impact Study Interim Report' was published on 1 December 1995, within days of my taking office and that my private secretary was sent a copy together with a briefing note on the report **[DHSC0042937_071]** (covering note); **[DHSC0042937_072]** /

[DHSC0042937_072] (briefing note); report **[HSOC0002726_002]**. I note from the records that I had requested the briefing note on the Impact Study during a briefing on 30 November 1995 for an oral PQ from John Marshall MP on Hepatitis C compensation. Similarly, I can see that one of the first PQs I responded to was a written response to Harriet Harman concerning what research was being undertaken in relation to the effectiveness of alpha interferon in the treatment of Hepatitis C (tabled 30 November 1995, answered 6 December 1995) **[DHSC0042259_177]**. This was in fact within Baroness Cumberlege's portfolio but it would fall to me to answer PQs tabled in the Commons.

2.4. So while I do not recall receiving any kind of 'set brief' on infected blood issues on arrival at the Department, it is clear that these were issues (amongst very many others) on which I was getting up to speed even in my first few days as Parliamentary Under Secretary for Health. I expect that the AHOs would have been mentioned as part of these early discussions and this is supported by the documentation I have seen in preparing this statement.

2.5. I deal further with the question of my general knowledge of the needs of those infected with HIV or hepatitis as a result of their treatment with blood or blood products from paragraph 2.10, below.

2.6. My own direct involvement with the AHOs (at this stage it was just the Macfarlane Trust and the Eileen Trust) was relatively limited. They had been set up before I became a Health Minister. I cannot recall any questions arising relating to their structure or activities which required my direct input, save for those I set out below at paragraphs 2.7 – 2.9 (appointment of Trustees) and paragraph Section 3: (funding of AHOs). I do not have any recollection of meeting with either the Chairs or trustees of the AHOs in that capacity. I should note that I did meet with Reverend Prebendary Alan Tanner, and had correspondence with him throughout my tenure, in his capacity as Chairman of the Haemophilia Society. At that time, he was also a Chairman of the

Macfarlane Trust, the Macfarlane Special Payments Trusts and the Eileen Trusts.

2.7. It was part of my ministerial responsibilities to appoint the Secretary of State-nominated trustees of the AHOs at such time as this was required. From the papers I have seen, I can see that I received submissions in relation to appointing/reappointing trustees to the AHOs on 13 February 1996 **[DHSC0003427_005]** and 9 May 1996 **[DHSC0003442_006]**. This latter submission addressed the nomination of two retired civil servants noting that,

> *"Both the other vacancies were previously filled by retired civil servants. The Department has considered it helpful that some trustees should have this background, and be fully aware of the political sensitivities of their work. We know that the trust have found their experience helpful. Our nominees for replacements are therefore both former civil servants."*

I received a further submission on appointments to the Macfarlane Trust on 18 February 1997 **[DHSC0003439_015]**. Appointments of this kind – while important – were fairly routine Ministerial business. As the endorsement on the submission shows, I agreed with the recommendations of my officials **[WITN5294006]**.

2.8. It was also part of my ministerial responsibilities to approve the funding requests from the AHOs. I deal with this under the subheading "Funding of the AHOs" at Section 3, below.

2.9. The Inquiry asks me to explain which issues relating to AHOs I would have dealt with personally and which would be dealt with by my officials, and in addition whether there were any criteria for matters being brought to my attention. Some matters had to be dealt with personally such as Trustee appointments because these required a nomination by the Secretary of State. That could be delegated to a junior Minister but not to an official. Agreement to significant spending was another example, and that explains why the AHO funding allocations came to me. On the AHOs as with other bodies, officials would have dealt with the more operational matters themselves. More generally, and outside of the specific context of AHOs, officials would use their judgement on when to submit matters to Ministers. Non-exhaustive examples would be: novel policies, significant changes of policy, significant spending, matters of likely controversy, and any specific areas that the Minister or their Private Office directed must be raised at Ministerial level.

2.10. I have been asked to explain my knowledge and understanding of the needs of those who had been infected with HIV and/or hepatitis from blood or blood products. I have also been asked about the source(s) of that knowledge and understanding.

2.11. As with my other parts of my portfolio of responsibilities, I would in the first instance and in general terms, have relied upon my officials with responsibility for that policy area to brief me on relevant topics, including (in this context) the needs of those infected.

2.12. I have already referred, for example, to the fact that I was sent a copy of the Haemophilia Society's Hepatitis C Interim Impact Study report on 1 December 1995. However, on 20 February 1996 I received further briefing on the final report from Kevin Guinness, Head of the Department's Corporate Affairs Operational Policy Unit ("CAOPU"), **[DHSC0004469_007]** (briefing) and **[HSOC0002726_001]** (report).

2.13. However, briefings from my officials were not the only source of my information. I would have gained knowledge of the needs of those infected with HIV and or hepatitis from a range of other sources, including:

(1) Material and meetings with the Haemophilia Society and direct correspondence with the Rev'd Tanner.

(a) I met the Rev'd Tanner and other representatives of the Haemophilia Society, on 26 March 1996 **[DHSC0002533_002]** (faxed briefing note from the Haemophilia Society) [4]

(b) As already noted, I had correspondence with the Rev'd Tanner including his letters of 18 June 1996 **[HSOC0014319]** and 3 October 1996 **[HSOC0014299]**.

(2) Meetings with other interest groups for example the Manor House Group whom I met on 20 March 1997 **[DHSC0006290_111]**;

(3) Letters from fellow MPs and from their constituents to my private office, and questions from fellow MPs in the House:

(a) An example of correspondence from an MP is Alice Mahon's letter to me of 12 July 1996 **[DHSC0041170_158]**.

(b) An example of correspondence from a member of the public, a haemophiliac infected with Hepatitis C through infected blood, is that dated 3 February 1996 **[DHSC0004740_026]** and 26 June 1996 **[DHSC0006961_050]**. I would not see all correspondence of this kind because some would have been responded to by officials.[5] Nevertheless, from the correspondence to MPs and other letters raised for personal replies from me, I would have read and understood the nature of the concerns (including patient needs) being urged upon us.

(4) Media reports and summaries which I would have read.

Consideration given to a payment scheme for Hepatitis C infected haemophiliacs

2.14. I have been asked about my involvement in the decision not to set up a payment scheme for haemophiliacs infected with Hepatitis C. As the Inquiry

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[4] General briefing notes and lines to take **[DHSC0002533_003]**, **[DHSC0002533_004]**, **[DHSC0002533_005]**, **[DHSC0002533_006]**, **[DHSC0002533_007]**.

[5] In the case, for example, an official Mr Levy replied to a letter addressed to me on 3 July **[DHSC0006961_048]**.

is aware, no payment scheme was set up during my time as the Parliamentary Under Secretary. I will set out first a chronology of what appear to be the main aspects of how this was considered while I was the junior Minister and then return to some further observations on this issue.

Chronology regarding the decision not to introduce a Hepatitis C payment scheme

2.15. The Inquiry refers me to a briefing to the Prime Minister dated 21 November 1995 **[DHSC0042937_057]**. This was just before I joined the Department but it shows the established Government position against the introduction of a Hepatitis C payment scheme:

> *"Compensation?*
>
> *What the hon. member is asking for is compensation for patients where, tragic though their circumstances are, no fault and no negligence on the part of the NHS has been proved.*
>
> *The House will understand the significance and implications of such a move. The principle involved is not one which can or should be lightly breached.*
>
> *My RHF SofS for Health has reiterated the policy of his predecessors, most recently in evidence to the Health Select Committee (July 1995), that he does not believe 'no fault compensation' is a sensible use of NHS resources.*
>
> *Precedent already established by HIV*
>
> *In the case of patients inadvertently infected with the HIV virus, the decision was taken, in light of their very special circumstances. Those affected were subject to significant social problems and were all expected to die very shortly."*

2.16. On 30 November 1995, my Private Office was copied into a minute from Mr Pudlo, a policy official in CAOPU. Mr Pudlo advised that the Haemophilia Society's interim impact report (to which I have already referred) was due to be published on 4 December. Mr Pudlo referred to the campaign by the Society for a Hepatitis C payment scheme and advised that the line should remain against such a scheme, "*...as no fault nor negligence on the part of the NHS has been proved there are no plans to make special payments*"

[DHSC0004498_141]. As I have indicated, I received a briefing on this report on 1 December 1995 in the context of an oral PQ from Mr Marshall **[DHSC0042937_071]; [DHSC0042937_047]**.

2.17. On 5 December 1995, I answered that PQ from John Marshall:

> *"Mr. John Marshall To ask the Secretary of State for Health, what representations he has received about making an ex gratia payment to haemophiliacs infected with hepatitis C. [2179]*
>
> *Mr. Horam Representations include seven earlier parliamentary questions, and five early-day motions. There was also an Adjournment debate initiated by my hon. Friend on 11 July and a short debate in another place. Ministers have received 291 letters.*
>
> *Mr. Marshall I congratulate my hon. Friend on his promotion to the Department of Health. Since his promotion, has he had a chance to read the impact study produced by the Haemophilia Society, which has been made available to his Department, which demonstrates the physical, financial and emotional hardship suffered by haemophiliacs? As the cause of that hardship, infected blood products, is the same as that which passed on the HIV virus to haemophiliacs, should not the Government's reaction be the same?*
>
> *Mr. Horam First, I congratulate the Haemophilia Society on its sensible review and my hon. Friend on his relentless questioning over many years, which has already achieved quite staggering results. I have not yet read the full review, but I shall do so as a matter of priority and I shall obviously take its conclusions most carefully into account.*
>
> *Mr. Mudie Does the Minister realise the stress caused to the families of individuals, such as a 13-year-old youngster in my constituency, who not only have to cope with haemophilia but have now been totally devastated by having to cope with the effects of hepatitis C? Please may we have an early and sympathetic decision to bring some hope to those families?*
>
> *Mr. Horam I assure the hon. Gentleman that the problem will always receive sympathy from me." (Hansard, 5 December 1995)*

One of the documents to which the Inquiry refers me is a partial copy of the briefing note I received for this PQ[6] but a fuller version appears at **[DHSC0042937_047]**.

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[6] **[DHSC0042937_051]**

2.18. On 13 December 1995, there was an adjournment debate on haemophiliacs secured by George Mudie MP, in which John Marshall also spoke. **[HSOC0002072]**. My response included the following:

> *"I know that many hon. Members are concerned about the situation of haemophiliacs who have also had the misfortune to contract hepatitis C, which adds to the difficulties that they already have to face. The problem has been raised several times in the House. Last week, I answered a question on the subject from my hon. Friend the Member for Hendon, South (Mr. Marshall), to which the hon. Member for Leeds, East added a supplementary question. My hon. Friend also initiated an Adjournment debate at the end of the previous Session. I am also aware of early-day motion 3, which has a large number of signatures.*
>
> *Let me say that I have great sympathy—and will always have great sympathy—for patients who have become infected with hepatitis C through blood transfusions or blood products. The Haemophilia Society originally launched its campaign for help for people in this situation in the spring. The hon. Member for Leeds, East will be aware that the Haemophilia Society has recently issued an interim report—I stress that it is an interim report—on its hepatitis C impact study.*
>
> *I have just come to the Department of Health, and there is a great deal to read. I would like to read the Haemophilia Society's report thoroughly, but I have not yet had the opportunity to do so. I shall make that a very high priority, but I want to read the report and not merely a brief. I am aware that the report graphically describes the problems experienced by some sufferers who find that they now have to contend with the effects of hepatitis C of infection on top of the effects of haemophilia. The hon. Member for Leeds, East graphically and eloquently explained those severe problems in his speech."*[7]

I should like to make clear – as I was candidly indicating in this debate – that an incoming Minister to a major Department has a great deal of reading to do. At this stage, I was aware of the content of the report from the briefings I had received, but I was indicating that I wanted to read it in full and not just the summary.

2.19. A little later in my reply, I gave way to John Marshall and there was this exchange,

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[7] An early draft of a speaking note for this debate prepared by officials is one of the documents to which the Inquiry has referred me **[DHSC0006774_066]**.

> *"Mr. John Marshall Does my hon. Friend agree that, if a relatively small proportion of sufferers will develop cirrhosis of the liver and die prematurely, the cost of helping them will be correspondingly small?*
>
> *Mr. Horam Yes. That is a valuable point, which my hon. Friend makes for the first time. The Haemophilia Society—understandably, as it has not completed its study—has not made full and costed proposals. We have never received such a suggestion to study, and I would be interested to hear details of the relatively modest and restricted proposal which my hon. Friend has made during the debate. We understand that the final report of Haemophilia Society will be published in 1996."*

2.20. On 14 December 1995, I sent a reply to Peter Butler MP who had written to the Minister of State Gerald Malone on 22 November 1995 on behalf of a constituent **[DHSC0004060_002]**. As the Inquiry will be aware, responses such of this would be drafted by officials in the first instance and the draft sent to me for approval. This letter would undoubtedly have reflected the Department's established position at the time against a Hepatitis C payments scheme. For example, the reply stated that we had no plans to make special payments and argued that the most effective use of resources was to seek to improve the understanding, management and treatment of the condition. As I address below, I wanted to soften this standard line in correspondence.

2.21. Reviewing the available papers, it is perhaps notable that on 18 December 1995, the Treasury (J W Grice) wrote to Mr Dobson in the Department to raise concern about what I had said in the adjournment debate on 13 December 1995 **[DHSC0042937_036]**. Mr Grice's concern was about the passage I have cited at paragraph 2.19, above. He told Mr Dobson,

> *"The Government has a firm and agreed policy on such issues. Consistent with that policy, and for the avoidance of doubt, I should indicate that the Treasury would be strongly opposed to what Mr Horam termed "the relatively modest and restricted proposal" made by Mr John Marshal MP."*

It is highly unlikely that I would have seen this minute. It was not copied to my Private Office and (given its content) is something officials would probably not have shown me. It has the hallmarks of the Treasury telling the Department that its new junior Minister had said something that risked straying from the accepted Government line on a spending issue about which the Treasury had strong views. This minute is certainly indicative of the strength of feeling in the Treasury about the cost and precedent implications of introducing a Hepatitis C payment scheme.

2.22. On 20 December 1995, Ann Towner, an official in the policy branch "CA OPU2" minuted Mr Pudlo and my Private Secretary in relation to the lines we were using in correspondence. **[DHSC0004498_051]**. She noted that I had indicated that I wanted to insert the words "*at present*" into the standard wording *"we have no plans to make special payments"*. Ms Towner was raising concern about what I had suggested,

> *"...we fear that if we were to qualify the existing line in correspondence as suggested, it would be taken as indicating a weakening of the Government's position, and imply that compensation is being considered and further continued pressure would lead to concessions.*
>
> *In view of the above, PS(H) may wish to discuss the proposed additional wording with SoS."*

Perhaps mirroring, in part, the Treasury's concern, this minute can I think fairly be interpreted as the policy branch (CA OPU2) urging that I should check the position carefully with the Secretary of State before pressing ahead with my proposed softening of the line in correspondence.

2.23. Similarly, I can see from the available records that on the same day, 20 December 1995, Mr Guinness forwarded Ms Towners minute to the Permanent Secretary's Office saying,

> *"The Permanent Secretary may wish to be aware of the attached minute. I mentioned to him the other day that PS(H) was clearly not happy with the firm line Ministers have taken up to now on compensation for haemophiliacs infected with hepatitis C. It is quite clear that he is trying to change the line, little by little. He has had plenty of briefing (written and oral) on the subject, but his sympathy for those concerned is clearly uppermost in his mind. Cost comes second – hence his readiness to consider proposals for a scheme limited to those who have actually developed chronic illness, rather than extending to all who have been infected. Secretary of State met a group of haemophiliacs (led by Roy Hattersley) yesterday, and made no concessions"* **[DHSC0004498_188]**.

2.24. I did not consider that I was trying to change the Department's main line. I was simply trying to explore if there were any more limited options available.

2.25. My Private Secretary clearly raised this with me and replied the next day, 21 December 1995 stating,

> *"PS(H) has seen Ann Towner's note of 20 December. Basically, he very much accepts the Department's stance on this issue, but does not want to give the impression that he is deaf to the concerns of the haemophiliac community. He said at the recent adjournment debate that he wanted to read the Haemophilia Society's report carefully, and would like to reflect that sort of attitude in the standard reply.*
>
> *However, he has noted your concerns about the wording he suggested and has asked whether you could propose an alternative form of words which would convey this."* **[DHSC0004498_045]**

This minute reflects that while I was very sympathetic to those infected with Hepatitis C through contaminated blood, I was fully aware of the concerns of the Department about cost and precedent. I was, however, fighting to avoid being pinned down to this until I read into the subject more widely and had a chance to consider whether there were any other options.

2.26. On 21 December 1995, I wrote to the Rev'd Tanner in response to his letter to Stephen Dorrell of 1 December[8] in which he had supplied the interim impact report **[HSOC0014333]** (letter) and **[HSOC0002726_002]** (report). This was in effect a holding reply, and I indicated that I would welcome a meeting with him in the New Year; we were eventually to meet on 26 March 1996 (see further below). I wanted to look carefully at the arguments for and against a payment scheme and this reply referred to the Government's current position but promised a meeting.

2.27. In order to be able to consider the Hepatitis C payment scheme question with appropriate care, I asked for a submission on the issue with costed options. The request was conveyed by my Private Secretary in her minute of 6 January

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[8] **[WITN5294007]**

1996 **[DHSC0003883_123]**. It was my initiative to pro-actively ask for this submission because I wanted the options to be costed, and I wanted to consider the matter fully. The request reflects that I was keen to look at what might be acceptable to the Haemophilia Society but also alert to the knock-on impacts on other areas of funding, and the potential problems of the precedent that might be set. Officials were given a month to produce the submission.

2.28. The Inquiry refers me to a minute from Kevin Guinness to Dr Rejman, a Senior Medical Officer within the Department, which on its face is dated 8 January 1995 but which, in context, is more likely to have been sent on 8 January 1996 **[DHSC0042937_032]**. My Private Office was not copied into this minute and I would not have seen it. Mr Guinness had been at a meeting with the Permanent Secretary (Sir Graham Hart) who was said to have been "*... pleased to note that PS(H) had now agreed a draft with which we were happy and that the Secretary of State had recently written in firm terms to the Prime Minister on a constituency case.*" It was reported that Sir Graham's view was that

> *"... if pressure continues, we shall eventually be forced to concede. It would be nice to do so in an orderly manner, but in practice, the Treasury would be unlikely to budge until such time as the political situation became so untenable that the Prime Minister decreed that something had to be done. For the time being, therefore, we should continue to hold the line firmly"*

Mr Guinness suggested to Dr Rejman that it would be wise to undertake some contingency work on the sort of scheme favoured by John Marshall.

2.29. I do not recall the discussion or meeting at which this compromise wording was agreed. I note however that I wrote to Tim Yeo on that same day, 8 January 1996 and used the modified wording, *"We are always ready to listen to further evidence but I have to say that on the basis of these facts we have no plans to make payments to such patients"* **[DHSC0004498_025]**. This wording was used in subsequent letters while the issue of whether to introduce a Hepatitis C payment scheme was under active consideration. For example, the Inquiry refers me to the letter dated 29 February 1996 which I sent to Mark Robinson MP **[DHSC0004728_130]**.

2.30. Within the available records, I note that there is a minute dated 9 January 1996 from Ann Towner to Mr Guinness and Karen Marsden **[DHSC0042937_035]**. This gave suggested information to re-assure the Treasury in response to their minute of 18 December 1996. It reflects that I had understood the arguments that my proposed change of wording could lead to an expectation of a change in policy. It suggested that officials would keep making clear to me the potential implications of introducing even a limited scheme, noting finally that, *"...of course PS(H) cannot alter the Department's policy without the agreement of SofS who – recent correspondence suggests – retains a firm line."*

I do not in fact recall what Stephen Dorrell's view was on this.

2.31. Within the available documents are a number of internal minutes which show that officials had started working up the submission that I had requested. The Inquiry has referred me to several of these. But these preparatory documents would not have been shown to me at the time. I have seen these documents for the first time during my preparation of this statement. They include:

(1) Mr Pudlo's minute of 18 January 1996 to Mr Blake in the Solicitor's Division **[DHSC0042937_021]**;

(2) Mr Guinness' minute to Mr Pudlo of 19 January 1996 **[DHSC0002550_064]**;

(3) Mr Guinness' minute to a wide range of officials seeking input on his draft of the submission **[DHSC0002533_147]**.

2.32. On 7 February 1996, Mr Guinness sent the submission to Sir Graham Hart, the Permanent Secretary, who it seems had asked to see the submission before it was put up to me **[DHSC0003883_107]**. One might surmise that this reflected a desire on the part of the Permanent Secretary to check that the arguments on cost and precedent were sufficiently clearly articulated in the draft submission before it was put up to me. The Permanent Secretary replied to Mr Guinness the same day **[DHSC0042937_013]**.[9] From the available papers I can see that there were other senior contributions, such as from the Deputy Chief Medical Officer Dr Jeremy Metters on 7 February 1996 **[WITN5294008]**.

2.33. Mr Guinness sent me the finalised submission on 9 February 2006 **[SCGV0000166_015]**. I will not repeat the entirety of the submission which should be considered in full. It was structured so as to provide:

- Information on the 'natural history' of HCV i.e. how its progression varied in different patients (submission, §5)
- The number of haemophiliacs infected with HCV (§6)
- The option of a scheme based on the lump sum elements of the HIV payments scheme (§§8-15)
- The option of a scheme based on the discretionary elements of the HIV payments scheme (§§16 – 21)
- The option of a scheme based on the Irish scheme (§§22-24)
- The possible reaction of the Haemophilia Society (§§25-28)
- The issue of those infected with HCV through blood transfusions (§§29 – 31)
- The issue of unquantifiable future claims (§§32-36)
- Finance (§§37-38)
- The policy on no-fault compensation (§§39-43).

I was advised that the submission had been cleared by the Permanent Secretary, by finance officials in the Department of Health and with the other Health Departments i.e. those in the Welsh Office, Scotland Office and Northern Ireland Office.

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[9] The reply from Sir Graham Hart to Mr Guinness is dated 6 February 1996, a day earlier than Mr Guinness' submission of his draft on compensation for haemophiliacs with Hepatitis C. One of the documents appears to be misdated but it is clear that the Permanent Secretary is responding to the contents of the submission dated 7 February 1996 **[DHSC0003883_107]**.

2.34. The conclusion section of Mr Guinness' submission stated as follows:

> *" • A scheme, which would be contrary to general Government policy on no fault compensation, could not be confined to haemophiliacs.*
>
> *• The options considered here for compensation for infection with hepatitis C would cost in the order of £72 million to £360 million, with regular payments costing perhaps an additional £280 million over the years (though not all this latter cost would come from the public purse).*
>
> *• Early indications are that only the most expensive scheme would be acceptable to the Haemophilia Society, but we shall know more when their own proposals are received.*
>
> *• A scheme based on infection alone would be heavily front loaded.*
>
> *• There would be incalculable repercussions for the future. The newly discovered hepatitis G virus alone could multiply the cost of compensating people infected through blood transfusion by 10 (giving a range of £400 million to £2,000 million for the lump sum options).*
>
> *• The costs of this and future schemes would reduce the amount of money available for patient care." (original emphasis)*

It is fair to say, therefore, that officials were giving me strong warnings about the costs and implications of introducing a Hepatitis payment scheme.

2.35. The Rev'd Martyn Smyth MP tabled on oral PQ asking when we expected to report on 'the departmental study on Hepatitis C and its treatment'. This was to be answered on 13 February 1996 **[WITN5294009]**. The Inquiry refers me a document which is undated on its face, **[DHSC0002419_037]**. This appears to be the background note in relation to this PQ. The question appears not to have been reached in oral questions on 13 February 1996.[10]

2.36. On 28 February 1996, my Private Secretary minuted Mr Guinness thanking him for the submission of 9 February **[DHSC0003883_101]**. She made clear that I wanted to consider the options carefully and that I would not be forming any firm views until after I had discussed the issue with the Haemophilia Society at the meeting which, at that stage, was planned for 6 March 1996. The main purpose of this minute was, at my request, to seek further

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[10] Find in Hansard - Hansard - UK Parliament

information from Mr Guinness. I was keen to explore whether there was merit in the kind of alternative approach suggested by John Marshall:

> *"... PS(H) would like to explore further the financial implications of John Marshall MP's suggestion that we should restrict payments to those who develop cirrhosis. Mr Marshall claims that the annual cost of such a scheme would not be excessive, since cases would develop over the years, rather than all at once.*
>
> *4. Your submission suggested that 620 haemophiliacs would develop cirrhosis over time. An average payment of around £60k to these would amount to about £37m in total. PS(H) is keen to get an idea of the likely annual cost - in short, how many people might be expected to develop cirrhosis each year? When we discussed this briefly yesterday, you made clear that this is a complex calculation which would need to take into account a wide range of factors. PS(H) understands this and appreciates that the information cannot be provided at once. However he feels that even a rough estimate will be essential if he is to answer the points made by Mr Marshall."*

2.37. The next day, the Permanent Secretary (who was copied into this minute), replied to my Private Secretary urging, "*extreme caution in dealing with Mr Marshall's proposal*" **[DHSC0003883_100]**. Explaining the Permanent Secretary's views, PS/Permanent Secretary wrote:

> *"2. He appreciates that it may be possible to devise schemes which cover only restricted groups and are thus more affordable. He does however point out that any move to pay compensation to a restricted group of Hepatitis C sufferers (eg haemophiliacs) is likely to lead to irresistible pressure to extend it to a much wider group. There is no obvious basis for distinguishing between people infected via blood products and those infected by blood transfusion, for example; and the Government was quite unable to sustain the same distinction in the case of HIV/ AIDS sufferers. The unfortunate truth is that this is a very slippery slope. Our present stance is uncomfortable, but any movement from it, however slight, is likely to start something we won't be able to stop.*
>
> *3. He therefore recommends extreme caution in dealing with Mr Marshall's proposal."*

2.38. On 5 March 1996 my Private Secretary minuted the Permanent Secretary in response, noting:

> *"PS(H) has seen your minute of 29 February setting out the Permanent Secretary's comments on the question of introducing compensation for haemophiliacs with hepatitis C.*

> *PS(H) has noted the points made by the Permanent Secretary and has commented that he will certainly bear these in mind. I shall keep you in touch with developments."* **[DHSC0003883_099]**

2.39. On 11 March 1996, Mr Guinness provided a further submission to my Private Office responding to my request for additional information on the financial implications of a scheme along the lines suggested by Mr Marshall **[SCGV0000166_005]**. Within this submission, Mr Guinness cautioned that:

(1) Such a scheme was unlikely to be acceptable to the Haemophilia Society;

(2) Was unlikely to be capable of being extended only to haemophiliacs;

(3) There would be difficulties in diagnosing cirrhosis reliably because this would require a liver biopsy which could not justifiably be required to be undertaken for the payment scheme, especially in the case of haemophiliacs (though some would have had a biopsy already). But paying on the basis of chronic liver disease rather than cirrhosis would increase the qualifying cohort to 50% instead of 20%;

(4) There would be significant complications in administering a scheme that included blood transfusion patients because of the difficulty of establishing causation. An appeals process would also be necessary; and

(5) The submission only addressed Hepatitis C but the newly identified Hepatitis G was more prevalent and had been shown to cause cirrhosis in some cases.

Against the background of these concerns, the estimated capital costs of such a scheme were tabulated in the submission as follows:

	Haemophiliacs £ million	Blood Transfusion Recipients £ million	Total £ million
Payable now	21	20	41
Payable each year until 2005	2	2	4
Payable each year from 2006 to 2011	0	2	2
Payable each year from 2012 onwards	0	*	*

* = less than £1 million.

2.40. The Inquiry has asked me about my recollections of a meeting which took place on 26 March 1996 between me and the Haemophilia Society, which was also likely attended by Departmental officials. I cannot specifically recall the meeting from independent memory, but I have reviewed the following:

(1) The covering note dated 20 March 1996 sent to me by Ms Towner **[DHSC0002533_002]**;

(2) The briefing which was attached to that note **[DHSC0002533_002]**;[11]

(3) Additional briefing, dated 21 March 1996, on the Irish scheme's first payments **[DHSC0042289_194]**;

(4) The Haemophilia Society briefing document which was shared with us at the meeting **[HSOC0014417]**;

(5) Letter from D. Wise, Secretary of Alfred Morris MP to Graham Barker at the Haemophilia Society with attached ministerial reply to a PQ tabled by Lord Morris **[HSOC0014171]**.

I have not seen a minute of the meeting in the available papers. A minute of this kind of meeting would ordinarily have been taken, usually by the Private Secretary in attendance.

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[11] The documents **[DHSC0002533_007]**, **[DHSC0002533_004]**, **[DHSC0002533_006]** and **[DHSC0002533_018]** to which the Inquiry has referred me appear to be extracts from this briefing.

2.41. It is clear to me from the papers I have seen that the Department considered the Haemophilia Society's work to be extremely important in supporting those infected with Hepatitis C from blood and blood products. From those papers, particularly the briefing document sent by the Haemophilia Society on the day of the meeting, it is apparent that we would have discussed their proposals for a compensation scheme, this being one of their central campaign items. From the Department briefing document, I think it likely we would also have discussed:

(1) Current treatment, counselling and management of Hepatitis C;

(2) Research;

(3) Public education;

(4) Funding the work by the Haemophilia Society; and

(5) Funding of recombinant products (and VAT).

2.42. I have been asked to describe what steps were taken after the meeting, as a result of the discussions. The question of a Hepatitis C payments scheme was already receiving much attention internally in the Department, at my request. Discussing the issue in person would have allowed me to better understand their views and inform the difficult decision that had to be made. On the other areas discussed, officials would have taken note of the points raised and factored them into work on those areas.

2.43. This meeting was not the end of the Department's contact with the Haemophilia Society. On 4 April 1996, Mr Pudlo sent a minute to my Private Secretary which reported on a further discussion that had taken place with Graham Barker of the Haemophilia Society on 3 April 1996. The discussions appear to have centred on obtaining more information around the type of scheme that would be acceptable to the Haemophilia Society. The minute reported that:

> *"3. The Society confirmed that the compensation they are seeking includes those haemophiliacs who have already accepted payment for HIV infection (notwithstanding the fact that this group had waived their legal rights to any further action against a Government Department*

> *arising from Hepatitis infection) and that a settlement that excluded this group would lead [to] a continued campaign on their behalf…*
>
> *3. In general the proposal is difficult to distinguish from the existing scheme for HIV infected haemophiliacs. Despite the additional refinement the estimates of cost are inevitably crude. The totals are higher than those predicted for an HIV-type scheme in Mr Guinness' submission of 12 February (£140m) for two reasons. Firstly this scheme includes additional payments to those already compensated under the HIV scheme and secondly the rates sought are somewhat higher.*
>
> *4. As an alternative and (mentioned at the meeting with PS(H)), the Society are attracted by the Irish scheme whereby an independent tribunal assesses payments according to the law of tort. The few payments made so far indicate that, if applied on similar principles in the UK the overall cost would be very much higher than any estimate made so far. As indicated in previous submissions and acknowledged by the Society, it would be very difficult to exclude non-haemophiliacs from any scheme. The effect would be to at least double the estimated costs."* **[DHSC0042289_176]**

2.44. The minute would have made clear to me that any payment scheme acceptable to the Haemophilia Society would be even more costly than those previously costed by the Department. The minute ended by stating that the Haemophilia Society acknowledged that the Department would need time to consider their proposals, given the large sums involved. I can see that Mr Pudlo enquired what further work I would like undertaken. From the available papers I cannot see a response from my Private Office but the events described below illustrate the further work that was undertaken by the Department through the rest of 1996 and early 1997.

2.45. I wrote to Mark Robinson MP on 22 April 1996, in response to his letter on behalf of a constituent **[DHSC0004728_050]**. The letter had originally been sent to Andrew Mitchell who was at that time Parliamentary Under Secretary of State for Social Security. I reiterated the current Departmental line, at that time, which was that there were no plans to set up a payment scheme and that the Government did not accept negligence. I explained that the Government had made payments in relation to those infected with HIV due to their special circumstances, with those affected (at the time) thought to have a very short life expectancy and who were subject to particular social problems, including ostracism. My letter set out that the Department was supporting an initiative by the Haemophilia Society to undertake a study into the best way to support its members who were infected with Hepatitis C and had made available £91,000 in 1995/1996, with a commitment to further funding through 1996/1997 and 1997/1998.

2.46. I also addressed in that letter a question regarding the levy of value added tax ("VAT") on recombinant Factor VIII and IX. I explained that:

> *"Questions of VAT are a matter for Customs and Excise. However, they have advised that all drugs and therapeutic substances supplied by manufacturers and wholesalers to hospitals are chargeable with VAT at the standard rate. Human blood and substances derived from it, including traditional Factor VIII, are exempt and are the exception and not the rule. Recombinant products, being synthetic and not derived from human blood, are, therefore, not within the exemption. Following advice from the Department of Health on the nature of these products, Customs advised suppliers that recombinant Factor VIII should be standard rated. This is in line with the VAT liability of these products in other Member States."*

2.47. Further work and meetings continued to take place. On 24 April 1996, Stephen Dorrell met John Marshall with Mr Pudlo in attendance **[DHSC0041255_074]** (meeting note) and **[DHSC0041255_074]** (briefing). I was not at this meeting. Mr Marshall set out details of the sort of scheme for which he had been previously seeking to gather support. He wanted the Department to explore a financial scheme based on lump sum payments being made to those haemophiliacs most severely affected and who went on to develop cirrhosis. As I have set out at paragraph 2.39 above, at my request, Mr Guinness had already provided a submission with officials' views on the viability of such a scheme.

2.48. The note of the meeting records that according to his own estimate, Mr Marshall's scheme would have cost around £18 million in the first year and £18 million over the next 10 years. The meeting note records that Mr Pudlo pointed out the difficulty of compensating only haemophiliacs and not widening the suggested scheme to encompass non-haemophilic recipients of blood donations. This, he said, would raise the costs to perhaps £40 million in year 1 and a further £40 million over the next 10 years. The note reports that Mr Marshall accepted that this distinction would be a difficult one to draw.

2.49. The Secretary of State is noted to have commented that:

> *"...whilst he was very sympathetic towards haemophiliacs with Hepatitis C, he did not consider that no-fault compensation of £40m would be an appropriate use of health resources. He made comparison with other needy groups (eg those requiring renal dialysis) who might enjoy a prolonged and better quality of life if £40m were available and it were invested on their behalf instead."*

2.50. It was agreed that Mr Marshall's best course may be to seek funds which had not been allocated for health purposes. Mr Marshall said that he would consider lobbying the Prime Minister for access to Government contingency funds. I note that Mr Marshall also raised the compensation schemes which had been set up by US pharmaceutical companies and suggested that these may provide a precedent for financing compensation to UK haemophiliacs. The Secretary of State agreed to ask officials to investigate the situation.

2.51. Minutes from Mr Pudlo to the Secretary of State's Private Secretary dated 1 May 1996 **[DHSC0003883_089]** and 10 May 1996 **[DHSC0042289_107]** confirmed that he had looked into Mr Marshall's suggestion regarding US pharmaceutical companies making payments. He could not find any information that would provide a precedent for a UK scheme to compensate haemophiliacs infected with Hepatitis C. The minute set out that the US payments appeared to relate to a joint settlement to conclude litigation by US haemophiliacs infected with HIV through blood products. In addition, the involvement of commercial companies reflected the differences between the healthcare systems in the two countries.

2.52. On 16 May 1996, the Prime Minister wrote to Mr Marshall stating that,

> *"The Government has given the question of compensation very careful consideration, including the Irish scheme. I have great sympathy but I really do think it is better to spend money provided for health care, from whatever source, on treating patients than on payments to people who received the best possible treatment available at the time. I am convinced that the best way we can provide practical help is to encourage research, and best treatment for those infected, as well as supporting, voluntary groups directly concerned with their care. We shall continue to support these efforts and explore other ways in which we can provide help."* **[HSOC0014325]**

The Prime Minister's reply would have been based on a draft supplied by the relevant officials in the Department of Health through the Secretary of State's Private Office[12].

2.53. On 29 May 1996 Mr Pudlo minuted my Private Office **[WITN5294010]**. He provided a draft letter to the Haemophilia Society in response to their compensation proposals. He noted that the response had been held over until the Prime Minister's letter to Mr Marshall had been sent. Mr Pudlo states:

> *"We agreed that I should submit a draft letter for PS(H) to consider once the PM had reaffirmed the Government's position to a settlement in his letter to John Marshall (sent 16 May) and this is now attached."*

The draft letter prepared by Mr Pudlo included the following suggested text,

> *"As you are aware I have been giving the matter of compensation very careful consideration in the light of the evidence submitted by your Society including the Hepatitis C Research Report. I have read the latter with great interest and appreciated the valuable insights that it gives into the range of problems affecting people living with haemophilia and Hepatitis C.*
>
> *As I have made clear in the House on a number of occasions I am very touched by the plight of those people and the circumstances in which they became infected. However, having weighed all the factors involved I have concluded that in allocating money provided for health care cannot justify taking resources away from treating patients in order to provide payments to people who received the best possible treatment available at the time. I also believe that the best way we can provide practical help is to encourage research, and best treatment for those infected, as well as supporting voluntary groups, like the Haemophilia Society who are directly concerned with their care. I can*

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[12] See the draft version of the response at **[DHSC0006947_156]**, and exchange of minutes at **[DHSC0006947_157]** and **[DHSC0006947_158]** and amended draft **[DHSC0006947_161]**.

> *assure you that we shall continue to support these efforts and explore other ways in which we can provide help."* **[WITN5294011]**

2.54. It seems clear that I did not send the suggested response. From the available records it looks as it this may well have been because, having earlier met the Haemophilia Society, I was also going to meet John Marshall on 25 June 1996. In that context, on 12 June Mr Pudlo sent me a briefing for that meeting **[DHSC0041255_073]**. This was supplemented on 17 June 2006 by a further note from Mr Pudlo warning that the Rev'd Tanner would soon be writing to press for a level of payment as an interim measure **[DHSC0042289_032]**.

2.55. On 18 June 1996 the Rev'd Tanner duly wrote to me **[HSOC0014319]**. He emphasised again the need for immediate Government action. Rev'd Tanner put forward an alternative scheme requesting a £20 million Trust Fund to meet the immediate financial needs of those infected and their dependants. In addition to this they requested a £10,000 ex gratia payment to all those infected with Hepatitis C through contaminated blood products. Rev'd Tanner described the proposed financial package as a "*modest one*" and one which would be the *"minimum required to alleviate immediate needs."*

2.56. A few days later, on 25 June, I met with Mr Marshall and Sir Geoffrey Johnson-Smith, who were advocating for the package set out in the Rev'd Tanner's letter of 18 June 1996 **[DHSC0041255_072]**. The meeting note describes the matters discussed, including the key demands:

> *"i) To award an additional £20m to the Macfarlane Trust to make provision for haemophiliacs facing hardship;*
>
> *ii) To award 10k to each haemophilic infected with HepC (total cost £30m)".*

2.57. The note records my comments, including:

> *"...that the demands put forward by the Haemophilia Society were very costly, especially since any award would have to cover infected non-haemophiliacs as well. On that basis, the total cost of the Haemophilia Society's demands would be £80m. Mr Marshall's own proposals for a*

> *scheme which restricted payments to those who had developed cirrhosis would cost £40m upfront, with another £40m over ten years. While this option would be cheaper in the short term, the cost would be similar over the longer term...it would be very difficult to justify payments of this magnitude with so many competing demands on the health service; this was money which might otherwise be spent on patient care."*
>
> *In response to Mr Marshall raising the possibility of Treasury funding, from the reserve, I am recorded as responding that,*
>
> *"...this was a matter for the Treasury, but [I] thought I was extremely unlikely to receive support."*
>
> *I also offered to investigate whether National Lottery funding would be appropriate while indicating that I was not sure whether this would be appropriate."*

2.58. The records show that I then had a meeting on 8 July 1996 at which the issue was discussed. I do not recall that meeting but it is evident that by this time I was inclined against agreeing to a payments scheme, at least one funded by the Department's resources. My Private Secretary minuted Mr Pudlo on 9 July 1996 **[DHSC0041255_070]**. She noted that:

> *"PS(H has now decided that he would like to write to the Haemophilia Society on Friday 19 July. Could you provide a suitable draft letter which:*
>
> - *stresses that we have considered their demands very carefully;*
> - *explains our decision not to provide compensation;*
> - *re-iterates our view that funds would best be spent on providing better care etc;*
> - *states that we shall look favourably on any future application for s64 funding for the Haemophilia Society.*
>
> *3. PS(H) has also asked that the letter should discuss the alternative options for funding suggested by John Marshall MP (National Lottery, Government contingency funds and settlements from drug companies). I am not sure whether these points have ever been raised by the Haemophilia Society itself. If not, and you consider it inappropriate, please let me know."*

2.59. On 9 July 1996, the Information Division suggested to my Private Secretary that the response should be deferred a little beyond 19 July because of the impending judgment in the CJD/hGH litigation **[WITN5294012]**.

2.60. On 29 July 1996 Mr Guinness sent a further minute to my Private Secretary **[DHSC0006348_055]**. The hGH/CJD judgment had been delivered and I had clearly asked for advice on whether the intended reply to the Haemophilia Society might be impacted by the judgment.

2.61. Mr Guinness advised, in essence, that this would not impact on the response to the Haemophilia society on the basis that the hGH/CJD judgment had found negligence. Mr Guinness did however raise whether the reply to the Haemophilia Society should be postponed. He was concerned that a response on the Hepatitis C payment scheme issue immediately after the hGH/CJD judgment might give rise to the perception that presented *"... the Government having forced one set of unfortunate people to endure the uncertainties of legal action now doing the same again."*

2.62. I can see that I requested a round-up of the current position on blood product issues and advice on whether "*in the light of recent events*" any amendments should be made to the proposed response to the Haemophilia Society. This resulted in a minute dated 11 September 1996 from Christine Corrigan, a policy official, to my Private Secretary **[DHSC0041255_064]** (minute) and **[WITN5294013]** (the note that was attached).

2.63. From the note that was attached to Ms Corrigan's minute, the recent events to which I referred were probably: the CJD/hGH judgment; a recall of blood products; three cases of haemophiliacs being infected with Hepatitis A at Manchester Children's hospital, and issues surrounding recombinant FVIII. The advice was that these issues did not call for the position to be reconsidered. Ms Corrigan advised against referencing the position on recombinants in the reply:

> *"However, while I appreciate PS(H)'s concern that his response should be as comprehensive as possible, I have discussed this matter with colleagues and we would strongly recommend to PS(H) that he should not add anything further on that issue, particularly as the message is another negative one..." (minute, §3)*

2.64. The minute provided suggested wording, had I wished to address that issue in the response and concluded by stating that Ms Corrigan understood that I was considering issuing the response letter that week.

2.65. I can see that the response was delayed by a week due to the Secretary of State wanting to dovetail my letter with his reply to Mr Hattersley MP on the same subject.[13]

2.66. The Haemophilia Society provided a briefing paper, to be presented at the Labour Party Conference, which took place in late September/early October **[HSOC0003901]**. This set out their arguments as to funding arrangements for recombinant Factor VIII. While the Inquiry has referred me to this paper, it is unlikely that I would have seen this at the time, or indeed known of its content. The Haemophilia Society was pressing for:

> *"...pressure on Trusts and Health Authorities to fund recombinant Factor VIII for all children as an immediate priority, and for all those with haemophilia as soon as possible.*
>
> *the backing of the Department of Health for the Centre Directors' guidelines on the use of recombinant products*
>
> *in the longer term, the Department of Health to take responsibility for funding haemophilia care (or at least the cost of recombinant) so that recombinant products were available to all those who wanted them throughout the country."*

The briefing went on to note that:

> *"At present over 260 MPs from all parties have signed an EDM calling on the Government to provide financial support to those infected."*

2.67. I then wrote to the Haemophilia Society on 1 October 1996 to convey the decision **[HSOC0023572]**. For ease of reference and because this was obviously an important letter, I shall set it out here in full:

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[13] See an email from John Holden, Private Secretary to the Secretary of State, to Christine Corrigan dated 17 September 1996 **[WITN5294014]** and an internal minute between my Diary Secretary and Ann Towner **[WITN5294015]**.

> *"I am writing in response to your letter of 18 June about haemophiliacs infected with Hepatitis C through NHS treatment.*
>
> *I am sorry that it has taken so long for me to respond formally, but I am sure you will appreciate that I needed to consider very carefully your proposals and their implications before deciding whether it would be right to alter our position on the question of compensation.*
>
> *After much thought, I have concluded that it would not be appropriate to offer financial compensation to haemophiliacs who have been infected with Hepatitis C. I will explain my reasons for this, but I should first stress that I shall continue to listen to the arguments and look at other ways in which we can provide help.*
>
> *I hope that I have already made very clear my deep sympathy for all those affected by this inadvertent tragedy. I have been very touched by the real problems that they clearly face and I am committed to doing what I can to help. In considering whether compensation is the right way to do this, two points have been apparent.*
>
> *Firstly, we do not accept that there has been negligence on the part of the NHS. Tragic though it is that the very treatment designed to help those patients infected should have caused them harm, there can be no question that they received the best treatment available at the time. That treatment was essential for their survival. As you know, we take a view that compensation is only appropriate where there has been negligence.*
>
> *If we were to provide compensation on the basis of non-negligent harm, this would very quickly develop into a general no-fault compensation scheme, which would be both unworkable and unfair. This is a point that was considered in relation to the settlement of the HIV cases. On that occasion we were convinced by the very special nature of the disease and by arguments that it would not lead to further similar claims for compensation.*
>
> *Second, all the proposals for compensation (and you will be aware that I have considered a wide range of options) involve the expenditure of substantial sums of public money. I have a duty to consider the effect of such a sizeable sum on other health service expenditure. That duty has led me to conclude that funds that are available to the NHS, from whatever source, are best used in direct patient care.*
>
> *You will also be aware that suggestions have been made for funding compensation from sources other than the NHS budget and I have given these careful consideration. Although theoretically possible, funding through the commercial sector or the National Lottery are not matters in which it would be appropriate for me to seek to exert influence. The first would be a matter for any companies involved and the second for the independent National Lotteries Board.*
>
> *Turning now to the other areas mentioned in your letter of 18 June, you identified a need to progress in a number of areas, such as the treatment and care of those infected, research and public education. I entirely share your aim to achieve progress in these areas. A key*

> *priority must be to improve our understanding of the disease. As you are aware, we have made available additional funds to aid research into Hepatitis C, its natural history and optimal treatment. Whilst primarily geared to improve the understanding of Hepatitis C generally, any developments from this will be important to co-sufferers of haemophilia.*
>
> *Secondly, whilst we do not, as a matter of policy, allocate resources to support specific patient groups, we have undertaken to look into any problems to access to the drug alpha interferon where this is clinically indicated for any haemophiliacs. I am glad to say that any problems reported to my Department have so far been readily resolved.*
>
> *One of the best ways to improve still further the treatments available is to establish the relative effectiveness of new treatments such as alpha interferon II. Local purchasers can then make informed decision [sic] on using resources for the most effective treatments available for both haemophilia and Hepatitis C. The Standing Group on Health Technology have identified the evaluation of the use of alpha interferon in the treatment of Hepatitis C as a priority for the NHS. This is being taken forward by the National Coordinating Centre for Health Technology.*
>
> *Similarly I believe that the public education, important as it is, can only proceed at a pace determined by our developing understanding. Information that is not founded on scientific evidence can do more harm than good, however well-intentioned. My Department and the Advisory Group on Hepatitis are keeping this area under regular review and leaflets providing guidance on the prevention of blood borne diseases are being updated to include specific mention of Hepatitis C.*
>
> *Finally, I would welcome any proposals you might have to provide continuing support to haemophiliacs infected with Hepatitis C as part of the Society's core activities. I see this as a useful and practical development, which would draw on the valuable findings of the research the Society has already commissioned. This is an area where resources can be directly targeted to provide practical help and improved services to infected haemophiliacs. I can assure you that I will take a very positive view of any application for further assistance from the Department under the Section 64 scheme, to take this forward.*
>
> *In view of the public interest in this matter, I hope you will not mind if I make the contents of this letter available on demand."*

2.68. The Rev'd Tanner replied to my letter very shortly after on 3 October 1996 **[HSOC0014299]**. He expressed deep disappointment with the Department's response. He made clear that the Society had never suggested that there had been negligence on the part of the NHS and that they sought a compassionate response to alleviate immediate needs. He also made clear their intention to push for central funding for recombinant products as well as continuing their campaign for financial help. My Private Office asked for advice and a draft reply from my officials.[14]

2.69. I was asked to appear on a World in Action documentation broadcast on 7 October 1996 to set out the Government's position in relation to treatment for Hepatitis C sufferers **[HSOC0008602]**. This was my first appearance on a television broadcast as a Health Minister. I was allowed a very short amount of time to answer a small number of questions put to me as part of the wider broadcast. I set out some of my contribution below as per the transcript available:

> *"V/O INT IAN HUNTER [presenter]*
>
> *All the haemophiliacs contracted hepatitis C as a result of receiving factor 8 through the NHS.*
>
> *SYNC JOHN HORAM*
>
> *Yes but…*
>
> *V/O INT IAN HUNTER*
>
> *30,000 of them.*
>
> *SYNC JOHN HORAM*
>
> *Yes indeed that is the case.*
>
> *V/O INT IAN HUNTER*
>
> *For a period and now they're dying.*
>
> *SYNC JOHN HORAM*
>
> *Yes. Remember they are alive first of all, I mean they've had the gift of life from the blood products they received, and in addition some of them have indeed got hepatitis C. But first of all they are alive and secondly the onset of hepatitis C, while very severe, in the case of probably one in five, undoubtedly, indeed leading to cirrhosis of the liver and death, er in many others is not so severe. So lets look at it in perspective.*
>
> *COMM*

---

[14] See handwritten comments on a copy of the Haemophilia Society's letter of 3 October 1996 stating *"1. PS(H) to write, 2. Mr Guinness to advice and a draft reply as appropriate please."* **[DHSC0041199_248]** (A462-A463*)*

> *…haemophiliac children at the same hospital have to go without recombinant treatment. Local Health Authorities say they can't afford it. Parents want the government to pay.*
>
> *SYNC JOHN HORAM*
>
> *…Local clinicians should decide whether someone needs the er new recumbent factor 8 or the existing one is satisfactory. Recognising that the new one is more expensive and therefore somebody else may not get treatment, someone whose dying of cancer for example, may never get the treatment they require.*
>
> *…*
>
> *COMM*
>
> *Every year the Department of Health spends £26 million on research into HIV and AIDS. So far, just one million points has been pledged towards researching the hepatitis C epidemic which scientist (sic) believe could affect more than ten times as many. The government say the scale of the problem has yet to be fully assessed.*
>
> *SYNC JOHN HORAM*
>
> *Speculation it is just that at this stage.*
>
> *V/O INT IAN HUNTER*
>
> *Well these are doctors…*
>
> *SYNC JOHN HORAM*
>
> *Yes but as we've seen over CJD and BSE experts are not always right.*
>
> *V/O INT IAN HUNTER*
>
> *Well they're clinicians, they're doctors, they're liver specialists. Don't you believe them?*
>
> *SYNC JOHN HORAM*
>
> *I take the view that we must see what's happening on the ground floor. Of course we are monitoring the situation very carefully. But at the moment we are not talking about those sort of numbers. We're talking about an increase, but a small increase. Let's watch what happens. It's a very difficult situation undoubtedly, we want to tread carefully and we will do that, we are doing that."*

2.70. On 14 October 1996, I wrote to Winston Churchill MP, responding to a letter he had written to Gerald Malone, enclosing one from a constituent **[DHSC0041256_026]**. The issue raised was payment of compensation for those infected with hepatitis C following blood transfusions. In my reply, I referred to my letter of 1 October to the Haemophilia Society and confirmed that

"...similar considerations apply in both cases." Namely, that whilst the Government has very real sympathy for those affected, they did not accept negligence on the part of the NHS and the proposals for a payment scheme had to be weighed against the other health service expenditure.

2.71. On 25 October 1996 I replied to the Haemophilia Society's letter of 3 October 1996 **[HSOC0003918]**. I confirmed that my reasoning held good whether the proposed payment scheme was deemed compensatory or otherwise. I emphasised that I remained ready to listen to any new points they wished to make and to look at other ways in which we could provide help through existing channels. I then addressed the issue of central funding of recombinant products for patients with Haemophilia:

> *"The Department's aim is to ensure that the best health care is obtained for the best resources available. We believe, as you know, that that aim is best achieved when decisions on appropriate treatments are made locally, taking account of the patient's individual needs, the alternative treatments available, and the availability of resources. Haemophiliacs are accordingly in no different position with regard to recombinant Factor VII than that of any other patient where alternative treatments are available."*

2.72. On 20 November 1996 I wrote to Douglas Hoyle MP, responding to his letter addressed to Stephen Dorrell on behalf of a constituent **[DHSC0046935_087]**. In that letter I set out that I had recently replied to the Haemophilia Society on the issue of financial help for those infected. My letter began:

> *"After much thought, I concluded that it would not be appropriate to offer financial compensation to haemophiliacs who have been infected with hepatitis C. I will explain my reasons for this, but I should first stress that I shall continue to listen to the arguments and look at other ways in which we can provide help."*

2.73. On 11 December 1996, there was a private members debate on haemophiliacs infected with Hepatitis C, which had been secured by John Marshal. I replied on behalf of the Government **[DHSC0041255_130]**. I set out again the Government's deep sympathy for those infected and the reasoning behind the Government's decision not to establish a payment scheme at that time:

> *"Health Ministers have had the opportunity twice this year to meet with my hon Friend to discuss these issues. The discussions which I have had with my hon Friend and with representatives of the Haemophilia Society have brought home to me very clearly the plight of those who find themselves infected with hepatitis C, in addition to suffering haemophilia. Nobody could fail to sympathise with the distress of people who, already suffering with one disorder, have found that the treatment for that disorder have given them another.*
>
> *That is especially true because factor 8 transformed the lives of many people with haemophilia – we should not forget that it greatly increased their life expectancy and improved their quality of life. It was undoubtedly the best treatment available for people with haemophilia in the light of medical knowledge at the time. However, medical procedures rarely come without risk, and those are not always known about or capable of being guarded against in time."*

Later I said that,

> *"... all the proposals for payment schemes involve the expenditure of substantial sums of public money. I have considered a wide range of options for such schemes - I really have done that - including the possibility of a scheme limited to those who go on to develop cirrhosis only. But they all have significant costs. As a Health Minister, I have a duty to consider the effect of such a sizeable sum on other heath service expenditure. That duty has led me to conclude that funds that are available to the NHS, from whatever source, are best used in direct patient care."*

2.74. On the same day the Rev'd Tanner wrote on behalf of the Haemophilia Society to the Prime Minister **[HSOC0000161]**. The letter comprised a petition calling for the Government to provide financial support for people with haemophilia infected with Hepatitis C through contaminated blood products. It stated:

> *"The Haemophilia Society and the Manor House Group – the special interest group within the Haemophilia Society of people with haemophilia and HCV – with widespread support among Members of Parliament. Over 270 MPs from all parties have signed an Early Day Motion in our support – yet still we are unable to obtain any financial help for those infected from the Government."*

2.75. I replied to the Rev'd Tanner's letter to the Prime Minister.[15] I set out the Department's position as follows:

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[15] The date of my reply is somewhat unclear. There is a version dated 19 December 1996 **[HSOC0000161]** and another version dated January 1997 in nearly (but not quite) identical terms, **[HSOC0000347_007]**.

> *"I acknowledge the concerns of those who have signed the petition you presented, and of the MPs who have signed Early Day Motions in support of your request that the Government make financial support available to those who have tragically been infected with hepatitis C through blood products. I have explained the Governments reasoning for concluding that it should not make such payments in my letter of 1 October, as well as during the debate in the House on the date of your letter, while stressing that I shall continue to listen to the arguments and look at other ways in which we can provide help."*

In relation to the comparison with those infected with HIV I wrote that:

> *"The decision a few years ago to make payments to those infected with HIV through blood products was, as I have said, taken in light of the assessment then of the very special nature of the disease, and of arguments that that payment would not lead to further similar claims. We are not convinced that hepatitis C falls into that same special category. At the time of the HIV settlement, it was believed that HIV would lead speedily to death and some haemophiliacs infected with HIV, especially children, were subject to some appealing examples of ostracism."*

2.76. The Inquiry refers me to a further letter from me to John Marshall (undated in the version provided to me but sent sometime prior to 23 March 1997), when Mr Marshall forwarded it to Mr Barker at the Haemophilia Society **[HSOC0004111]**. I set out there a further response to calls from Mr Marshall for a hardship fund:

> *"The cost of providing a hardship fund to those infected with hepatitis C through blood products – or through blood – would, as you imply, be less than that of some of the alternative schemes which have been suggested. Nevertheless the sort of sums you mention are not insignificant, and they are sums which as I have said before, were they available for use in the NHS, could be used to provide direct patient care.*
>
> *In any event, provision of a hardship fund with comparatively low costs does not remove the fact that providing a payment scheme in respect of non-negligent harm in one area could appear to pave the way for provision of a similar kind in others. As I have explained in my letter to the Haemophilia Society, which I copied to you, we do not think it appropriate to make financial provision in such circumstances."*

2.77. I can see that whilst the request for a hardship fund would have cost less than some of the alternative schemes proposed, it was still a substantial sum which would have had to be balanced against the Department's budget as a whole. The response therefore remained the same as my letter of 1 October 1996 to the Rev'd Tanner.

Commentary regarding the decision not to introduce a Hepatitis C payment scheme

2.78. Having addressed the chronology in some detail, I return to the specific issues and themes raised in the Inquiry's request.

2.79. I am asked to explain the rationale behind rejecting calls to set up a Hepatitis C payment scheme and to what extent I agreed with that rationale.

2.80. As I hope the chronology set out at paragraphs 2.14 - 2.77 makes clear, the rationale for the decision not to introduce a payment scheme for those infected with Hepatitis C through infected blood and blood products rested, in essence, on two key factors:

(1) The proposed costs of the various payment schemes when considered against other health spending, and

(2) The government's opposition to no-fault compensation.

2.81. In respect of (1), I requested officials to provide costed options and the result was that in their estimation the costs would have been approximately £72 million to £360 million, with regular payments costing perhaps an additional £280 million over the years. There seemed to be no realistic prospect of the Treasury funding the scheme so all costs would have come out of the Department of Health's budget, which would otherwise be used for patient care. Equally, there seemed to be no realistic prospect of getting the private sector to fund such a scheme because officials had established that private pharmaceutical companies in the US were funding payment schemes as they the UK. In respect of (2) I was advised that setting up such a scheme, when no negligence had been accepted on the part of the NHS or the Department would open the doors to further claims for similar payments schemes in different health spheres. These were the key considerations in reaching the conclusion against a hepatitis C payment scheme and it is my understanding that the same conclusion had been reached by my predecessor health ministers and by subsequent health ministers up until 2003.

2.82. The Inquiry specifically asks me about the minute from Mr Guinness dated 20 December 1995 which I have addressed at paragraph 2.23 above **[DHSC0004498_188].** Mr Guinness suggested that I was trying to change the Departmental line, little by little. But as I have explained, I was simply trying to explore if there were any more limited options available. It is certainly true that the Department's policy on compensation was that it had no plans to set up a scheme of any sort. I certainly recall that when I became aware of this issue, through the various sources I referred to at paragraphs 2.11 - 2.13, I wanted to keep an open mind. I did not simply accept the Departmental line without wanting further investigation. This is at the heart of why I asked for my officials to prepare the briefing of 9 February 1996 with costed options looking at all the potential alternatives **[DHSC0003883_123]**. Until I had that information I did not consider myself informed enough to come to any conclusions. Whilst I appreciated that there may be other political pressures at play, not least from the Treasury, I considered that I should look at the issue afresh. Mr Guinness suggested in his minute that *"...sympathy for those concerned is clearly uppermost in his mind. Cost comes second".* I certainly did have a great deal of sympathy for those infected with Hepatitis C as a result of contaminated blood and blood products and I was prepared to listen to arguments from all sides. But it was not a case of cost coming second, rather, like any Minister, I had to form a judgement based on all the factors.

2.83. I am specifically asked whether my stance to establishing a compensation scheme for haemophiliacs infected with Hepatitis C changed during my tenure at the Department.

2.84. I would not characterise my stance as changing. It was not the case that I was in favour of a scheme when I first took up post and then changed my mind and decided against it. Rather, I started from the position of wanting to keep an open mind and considering all the options. Then, once my officials had prepared the briefing note setting out the potential payment options and I had pressed for further information, I was able to consider the financial implications of any such scheme in the round, with other competing priorities for the Department and public health at the time.

2.85. The Inquiry asks whether my stance was shared by others in the Department. I cannot specifically recall anyone expressing a personal opinion to me on this. I generally found my officials to be skilled in presenting the information requested in a dispassionate way, notwithstanding the very difficult nature of the subject matter being discussed. In preparing my statement and reviewing the available documents, it is clear that officials were concerned in late 1995 and early 1996 that – as they saw it – I was not following the established government line. The degree of tension evident in late 1995 early 1996 arose because I was keen to communicate that I was willing to consider the issue afresh. They were plainly concerned that even communicating this openness to further consideration might increase the pressure. There was also perhaps an element of their thinking that as a Minister new to the Department I had not yet understood the costs and policy implications of agreeing to such a scheme. In fact, I was aware of those concerns, but I did want to look carefully at the options.

2.86. The Inquiry asks me about my meeting with the Haemophilia Society on 26 March 1996 and I have addressed this at paragraphs 2.40 – 2.42, above. I would only add that:

(1) There was regular contact between the Haemophilia Society and the Department but I think the meeting of 26 March 1996 was the only one that I personally attended.

(2) My officials met with the Haemophilia Society following the 26 March meeting in order to obtain further information about the sort of financial scheme that would be acceptable to their members, as I describe at paragraphs 2.43- 2.44 above.

(3) The period of time between my meeting with the Haemophilia Society on 26 March and my formal response regarding a payment scheme on 1 October 1996 arose because of the ongoing work which I have set out more detail on at paragraphs 2.44 – 2.66 above. Amongst other factors, the further meetings with John Marshall, looking into the pharmaceutical industry's contribution to schemes abroad, the Haemophilia Society's further letter of 18 June and consideration of other factors impacting our decision making such as the hGH/CJD judgment, all played a part in the length of time it took to issue a formal response.

2.87. The Inquiry refers me to Mr Pudlo's minute of 4 April 1996 in which he asked if there was further work that I would like officials to undertake, as I have set out at paragraph 2.44 above. While I cannot see a specific response from my Private Office to Mr Pudlo's minute in the available documents, the chronology I have set out illustrates the further work and considerations that were ongoing before I issued the Department's official response on 1 October 1996.

2.88. The Inquiry has referred me to the exchange of letters between myself and the Rev'd Tanner. In particular:

(1) The Revd Tanner's letter of 18 June 1996 which I have addressed at paragraph 2.55 above **[HSOC0014319]**. He outlined, in financial terms, the Haemophilia Society's proposal for an HCV payment scheme.

(2) My letter in response dated 1 October 1996 which I have addressed at paragraph 2.67 above **[HSOC0023572]**.

The Inquiry asks whether I agreed that the Haemophilia Society's proposals as to a financial package were "*modest*" as the Revd Tanner had suggested. I have also been asked how the Department reached its decision and what research was undertaken to support the arguments against the scheme.

2.89. I did not consider the financial package proposed by the Haemophilia Society to be modest. Their proposal in that letter was for a £20 million Trust Fund with an additional £10,000 ex gratia payment to all those who had been infected with Hepatitis C. Those were not insubstantial sums. They also made clear that this would not meet the long-term financial needs of those they represented. My officials also pointed out that it would not be viable to get up such a scheme without including those non-haemophiliacs infected. This would increase the cost of the proposed scheme to £80 million.

2.90. In respect of how the Department reached the decision which was set out in my letter of 1 October 1996, I think the chronology which I have set out at paragraphs 2.15 – 2.66 above illustrates how my opinion was formed. The costing options provided in Mr Guinness' submissions of 9 February and 11 March 1996 were sobering. With initial costings standing at between and £72 million - £360 million, with regular payments costing an additional £280 million over future years. The more limited costings for those with advanced liver disease, which had various practical problems in implementing were reported to be £41 million lump sum payments and then a further £4 million per year until 2005. Added to this was the uncertainty about the newly identified Hepatitis G and the impact this may have on future settlements. Those submissions, as well as many other submissions and briefings I received stated, as a real concern, the issue of setting a precedent in relation to no fault compensation for the NHS.

2.91. The Inquiry asks me about the consideration given to alternative schemes to that proposed by Rev'd Tanner, for example, a scheme for only those with cirrhosis or a hardship fund and no lump sum payments.

2.92. As I have set out in the chronology my Department did consider a range of schemes. John Marshall's proposed scheme, limited to those who had developed cirrhosis, while requiring less funds, was not thought to be workable in practice. After I had received the costs options in the 9 February 1996 submission, my Private Secretary's minute of 28 February 1996 shows that I wanted further exploration of Mr Marshall's suggested approach: see paragraph 2.36 above **[DHSC0003883_101]**.The submission in reply on 11 March 1996 sets out why officials had significant reservations about this approach: see paragraph 2.39 above **[SCGV0000166_005]**. The Secretary of State then met with Mr Marshall on 24 April 1996 to discuss his proposed scheme: see paragraphs 2.47 - 2.50 above **[DHSC0041255_074]**. I met Mr Marshall on 25 June 1996: see paragraph 2.56 above **[DHSC0041255_072]** (189). The difficulty with the scheme was that there was no obvious reason why the scheme should be limited to only those with haemophilia, such inclusion would raise the cost to £40 million in the first year and £40 million over the next 10 years. In addition, there were practical difficulties with the scheme which I have addressed at paragraph 2.38 above.

2.93. My consideration and response to the proposals for a hardship fund are set out at paragraph 2.76 - 2.77, above. These costings provided by the Department included schemes with a lump sum payment as well as ongoing support.

2.94. The Inquiry asks me about the further correspondence I had with the Rev'd Tanner between 3 October 1996 - 19 December 1996. I have addressed these letters in the chronology. I am specifically asked:

(1) Why I thought that setting up a payment scheme for HCV sufferers *"would very quickly develop into a general no fault compensation scheme which would be both unworkable and unfair*".

(2) Whether consideration was given to the Haemophilia Society's argument that they were not "*seeking compensation*" but were asking for a "*compassionate approach*" based on "*strong moral arguments*" and if so, how this was balanced against other factors.

(3) What I believed to be the main differences between the two viruses HIV and HCV and what let me to believe that there was less stigma attached to Hepatitis C.

2.95. In relation to the argument that setting up a payment scheme for those infected with Hepatitis C would lead into general no fault compensation, I was persuaded by my briefings that this was a real probability. Notably, paragraph 32 of the 9 February 1996 submission had stated:

> *"Unquantifiable Future Claims*
>
> *32. The opening of the door to future claims for no-fault compensation has previously been a matter of great concern to Ministers. There are a number of aspects to this.*
>
> *33. First, HCV can be transmitted not only through blood and blood products but through any transplanted tissue.*
>
> *34. Secondly, other viruses and infectious agents can be transmitted by blood or tissue. A new strain of hepatitis virus (HGV) has just been identified. It is far more prevalent than HCV; there is as yet no simple test for it; and, whilst its natural history is obscure, it has been shown to cause cirrhosis in some cases (the proportion is not yet known)…*
>
> *35. Third, potentially, the whole question of compensation for medical accidents is opened up. Haemophiliacs received the best possible treatment – treatment which prolonged their life. If they are to be compensated, who else should be? People who have been harmed by radiotherapy treatment? The patient who suffers from complications of surgery.*
>
> …
>
> *36. More specifically, PS(H) will be aware that litigation is being taken against the Department and the Medical Research Counsel in respect of patients treated with human growth hormone (hGH). In this case, we are awaiting advice for lawyers on the question of negligence. When considering a possible compensation scheme for Haemophiliacs, it would seem inevitable that similar arrangements may need to be concluded for hGH patients. Some 2,000 patients were treated with growth hormone, 16 died of CJD already and, on past experience, it is possible that another 33 patients may yet contract the disease."* **[SCGV0000166_015]**

2.96. The above points were compelling arguments at the time. Perhaps, in hindsight, the assessment was too pessimistic. At the time I took the warnings of my officials seriously.

2.97. In relation to the distinction between compensation and ex gratia compassionate payments, I believe we were aware that the Rev'd Tanner was not seeking compensation payments based on a finding or assertion of negligence but was seeking ex gratia payments on compassionate and moral grounds. I have set out my great sympathy, at the time and today, for those impacted by infected blood products. The meetings I had with the Haemophilia Society and John Marshall, along with all my other briefings brought home to me the difficulties faced by those infected.

2.98. In relation to the differences between HIV and Hepatitis C and the stigma attached to each, my knowledge would have come from my Departmental briefings and my own experience and awareness. I was not in office when the HIV litigation was settled but I was aware that, at the time, the life expectancy and quality of life was thought to be much less for those with HIV than for those suffering with Hepatitis C. My briefings suggested to me that, whilst some Hepatitis C sufferers would go onto develop cirrhosis of the liver, many would have few symptoms, for many years. The overall impression at that time was that there was more stigma associated with HIV than with Hepatitis C. Public education campaigns were on our agenda to increase awareness and provide reliable information about methods of transmission. However, it was I think common experience that AIDS and HIV had attracted, especially in the very early years a particularly marked level of stigma **[DHSC0006774_048]**.

2.99. I am asked about the consideration given to the Early Day Motion, signed by over 270 MPs as of 11 December 1996, calling on the Government to provide financial support to those infected with Hepatitis C. I discuss the Early Day Motion and my response at paragraph 2.75. I was not unaware of the strength of feeling on this issue, however, the matter had been given great consideration and no fresh arguments had been raised since my response letter to the Haemophilia Society of 1 October 1996.

2.100. I have been asked by the Inquiry to outline to what extent my answers on the World in Action documentary were arguments which influenced the Department's decision making on this issue. I have set out my comments in detail at paragraph 2.69 above. Leaving to one side the precise phraseology (which I address below) the underlying rationale for my comments in the World in Action programme was in line with my own and Departmental thinking.

2.101. My comments on that programme, made in response to questioning on a television broadcast, without adequate context may appear, in retrospect, rather blunt. I was not allowed time to set out my thoughts more extensively, rather as I would do in the House or in a letter. I think my position, and the Department's, was phrased better when I said the following to the House on 11 December 1996:

> *"Health Ministers have had the opportunity twice this year to meet with my hon Friend [Mr John Marshall MP] to discuss these issues. The discussions which I have had with my hon Friend and with representatives of the Haemophilia Society have brought home to me very clearly the plight of those who find themselves infected with hepatitis C, in addition to suffering haemophilia. Nobody could fail to sympathise with the distress of people who, already suffering with one disorder, have found that the treatment for that disorder have given them another.*
>
> *That is especially true because factor 8 transformed the lives of many people with haemophilia – we should not forget that it greatly increased their life expectancy and improved their quality of life. It was undoubtedly the best treatment available for people with haemophilia in the light of medical knowledge at the time. However, medical procedures rarely come without risk, and those are not always known about or capable of being guarded against in time."* **[DHSC0041255_130]**

2.102. I am referred to my letter to Winston Churchill MP dated 14 October 1996 which stated that there would not be a compensation scheme for those who had been infected with Hepatitis C via blood transfusion: see paragraph 2.70 **[DHSC0041256_026]**.

2.103. The Inquiry asks what consideration was given to a scheme of payments for those who had been infected via transfusion. While the Haemophilia Society was a prominent campaigner in this area, we recognised throughout that it was not going to be viable or justifiable to limit any payment scheme only to haemophiliacs infected through blood products. Our consideration therefore extended to all groups infected whether by blood products or whole blood transfusion. I can see from the 9 February 1996 submission from Mr Guinness, that this is made very clear at §29-§30. **[SCGV0000166_015]**.

Hepatitis C Research

2.104. I have been referred to the Parliamentary debate on 13 December 1995 **[HSOC0002072]**, where I referred to the Department looking at what research may be undertaken to increase knowledge of hepatitis C, its natural history and its optimal treatment. I am asked what research was undertaken and what the outcome was.

2.105. I can see a number of initiatives set out in a briefing paper prepared ahead of a meeting between the Secretary of State and John Marshall, discussed further above at paragraph 2.47 **[DHSC0041255_074]**. That paper listed the following areas of action to improve the treatment of Hepatitis C at §2.8:

> *"(i) Support for an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with the virus, with a grant of over £90,000 this financial year and £117,000 in 1996-1997 (on top of core funding of £35,000 this year and £38,000 in 1996-1997).*
>
> *(ii) With other Health Departments – a UK wide look back exercise to trace, counsel, and where necessary treat those who may be at risk of hepatitis C through blood transfusions. The start of the exercise was announced on 4 April 1995.*

> *(iii) Support for the British Liver Trust with assistance through the Sec 64 grant scheme. This includes a grant specifically to deal with the additional workload of advising patients infected with the virus.*
>
> *(iv) The Standing Group on Health Technology have identified the evaluation of the use of alpha interferon in the treatment of hepatitis C as a top priority for the NHS. This is being actively taken forward by the Medical Research Council.*
>
> *(v) Work is being taken forward to establish a national registry of transfusion acquired Hepatitis C infection of a known date of acquisition.*
>
> *(vi) Research proposals are being sought on establishing the prevalence, transmission routes and natural history of Hepatitis C infection.*
>
> *(vii) A ministerial commitment to investigate allegations of problems of access to alpha interferon. A few cases have been identified by the Society, all of which have been resolved."*

2.106. My reply to Mr John Heppell's PQ, for answer on 16 July 1996 regarding what actions the Government had taken to encourage (a) research and (b) best treatment for those haemophiliacs with Hepatitis C was as follows:

> *"I refer the hon. Member to the reply I gave him on 15 July. An additional £1 million has been made available by the Department's research and development division to fund research into improving our understanding to the prevalence, transmission and natural history of hepatitis C virus infection. The national health service standing group on health technology has identified the evaluation of the use of alpha interferon in the treatment of hepatitis C virus infection as a top priority for research. This is being actively taken forward by the Medical Research Council. A trial development group has met with researchers to help them in the design of a clinical trial. It is intended that patients with haemophilia will be invited to enter the trial. The Medical Research Council is also funding a three-year study to investigate the course and complications of hepatitis C virus-induced liver disease in a group of infected haemophilia patients. In addition, the Department is giving grant support to voluntary organisations working with those infected with hepatitis C."*[16]

2.107. The Department also provided relevant Section 64 funding. I can see that in addition to its Core Grant, the Haemophilia Society was provided with a project grant of £60,000 in the 1997/1998 budget year (see the minute of 12 December

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[16] Written Answers - Hansard - UK Parliament column 492.

1996 with a revised submission **[WIT5294016]** and confirmation of my approval on 3 January 1997 **[WIT5294017]**. The project grant related to the Haemophilia Society's Hepatitis ABC project, which aimed to identify the needs of haemophiliac patients co-infected with Hepatitis C.

2.108. In addition to the above, I provided a note to the Secretary of State on 23 January 1997 **[DHSC0006855_008]**. My note to Mr Dorrell attached a submission entitled "Hepatitis C (HCV): the Current Position". The underlying submission had been drafted by officials and sent to me and the other Ministers on 23 December 1996 **[DHSC0004203_013]**. It provided a framework for handing the disease and options going forwards. I can see in the papers an email sent on 8 January 1997 from Ms Claire Phillips, a research official, to a number of other Department officials which discussed this submission and stated:

> *"I met PS(H) this morning to talk about the hep c submission (which, as you may have noticed, I rewrote yet again). He is putting this up to SofS tomorrow. One of the issues he raised is the possibility of spending more on research than the money we are currently (£1m plus whatever the HTA costs – say, £1.3 altogether). He asked whether this would be useful and I said that it certainly would in terms of presentation to the profession as well as helping us to the address the problems that hepatitis C presents.*
>
> *He will discuss this with SofS but I thought I would warn you of this possibility. I am not sure how far we have [got] with awarding contracts for the research that we started to commission a year ago – were there many/any good proposals that we couldn't fund? Would it be possible to revive some of them? My recollection was that the sero-prevalence work was going to cost more than we had anticipated leaving less for the other work on transmission and natural history. On the treatment element, we are writing to the Wessex IPH to ask if we can meet them to discuss the proposals for the HTA into Alpha- Interferon"* **[DHSC0006855_008]**

2.109. In my note to the Secretary of State, I carried through this concern to increase research spending. At §7 I suggested:

> *"£1m has been allocated for research into the actual extent of Hepatitis C infection in the population, and its natural history and routes of*

> *transmission, but this seems inadequate in comparison to the much higher amounts (£25m) allocated for research into HIV/AIDS.*
>
> *Overall, our position of reviewing the situation together with supporting the development of clinical guidelines seems reasonable, provided that we can ensure that decisions about Hepatitis C treatment remain in local hands, and that we are kept aware of any hard cases which arise. However, I think that we could improve our position by increasing the amount spent on research into Hepatitis C. I suggest that officials could be asked to look at increasing the resources available for this."* **[WIT5294018]**

2.110. I met with the Secretary of State on 12 February 1997. I cannot now recall the meeting but the meeting note I have seen in the papers records:

> *"On research, Ministers were made aware that the Department Research Committee was meeting on Friday and this topic would be raised. Secretary of State said his assessment of this paper was that there was a need to develop a properly coordinated R&D programme on HCV as it was obviously an emerging public health issue. He could not make a judgement of its relative priority but nevertheless it should be addressed."* **[DHSC0004203_004]**

2.111. The overall position would appear to have been, therefore, that some further research had been commissioned by the Department and that in reviewing the wider Hepatitis C picture in early 1997, I had pressed the case for increasing the resources for this leading to the Secretary of State endorsing the need for a properly coordinated R&D programme on HCV, albeit that its priority would have to be judged against other areas.

Hepatitis C Lookback Exercise

2.112. The Inquiry have referred me to a submission headed 'Interim Report on the Hepatitis C Lookback Exercise' from Dr Rejman dated December 1995 **[DHSC0003533_010]** and what the Inquiry suggest was the reply to that submission from my Private Secretary dated 4 March 1996 **[DHSC0002533_152]**.

2.113. In fact, the available records show that Dr Rejman's submission of December 1995 was only a draft and was never sent to me in that form. It appears that the submission was reviewed and taken over by Dr Metters the DCMO. It was not put up to my Private Office until 5 February 1996 **[DHSC0004469_013]**. By the time of this finalised submission of 5 February 1996, there had been a further meeting of the Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation (MSBT). This is of some significance because Dr Metters' finalised submission was able to refer to the advice of the MSBT in a way that Dr Rejman's draft submission had not. My response of 4 March 1996 therefore needs to be understood in light of Dr Metter's final submission and not the draft submission to which the Inquiry's request referred me.

2.114. Dr Metters' submission was a 'for information' submission. The introductory paragraph read *"No action is required, although Minister may wish to meet with officials to discuss this report."*

2.115. The submission sets out the background to the lookback exercise, which had been instigated to identify those blood transfusion recipients infected with Hepatitis C prior to the introduction of screening in late 1991. The exercise was recommended to ministers by the MSBT in late 1994 on the basis that the feasibility of the Lookback has been demonstrated by a study in Scotland and that Interferon had been licensed in the UK as a potential treatment for Hepatitis. Ministers had agreed to the Lookback and the exercise was announced by Government in January 1995.

2.116. The interim report set out detailed information on progress, difficulties faced with the exercise and a proposed way forward. Under the heading "Reasons for slow progress", Dr Metters explained that:

> *"10. Members of the MSBT considered why the exercise was taking longer than originally envisaged. They identified two particular bottlenecks, one was tracing medical records of recipients identified in the hospital blood banks and, secondly, a shortage of counsellors available to see patients prior to and post testing.*

> *11. The MSBT accepted that if both of these areas of difficulty were overcome, it was likely that the hepatology services for specialist assessment and, where appropriate, commencement of treatment would probably not be able to cope."*

2.117. Under the heading "Alternate Ways Forward", Dr Metters stated:

> *"12. The MSBT felt that there were several options available. These are detailed in Annex F. <u>Overall MSBT's view was that central exhortation to speed up the process was unlikely to achieve much</u>. They were strongly against abandoning the planned Look-Back. It was felt that communications between the BTS and hospitals where there were particular problems was the best way forward, supplemented by the offer of assistance to overcome the bottlenecks in tracing hospital records and a shortage of suitably trained counsellors.*
>
> *13. The Committee felt that a delay in identification that might be extended for the rest of 1996 would not disadvantage patients as the evidence was of a 20-30 year time frame for significant liver damage to occur.*
>
> *14. Officials agreed with MSBT's view, but if Ministers wish to expedite the Look-Back programme, some or all of the actions proposed in Annex F could be introduced." (emphasis added)*

2.118. Annex F, which sets out the various options contained the following:

> *"1. Continuing Look-Back using the present strategy, but with central exhortation to speed up the process.*
>
> *2. Abandon the Look-Back entirely and offer hepatitis C tests to anyone who has been transfused.*
>
> *3. Continue with the Look-Back but offer assistance to overcome the bottlenecks due to problems in tracing hospital records and a shortage of suitably trained counsellors.*
>
> *4. The committee considered these options, but unanimously concluded it was important to continue with the present strategy. This has been carefully designed to identify and offer counselling and treatment to recipients of blood transfusion units implicated in the Look-Back in a structured way that would maximise benefits to them. At the same time the Look-Back would obtain important information about the rate of transmission and natural history of Hepatitis C when acquired from transfusion that was not currently available.*
>
> *5. The Committee also agreed that a delay in the identification process that might be extended for the rest of 1996 would not disadvantage patients as the evidence was of a 20-30 year time frame for significant liver damage to occur.*

> *6. Should Ministers feel action needs to be taken to overcome bottle-necks in the present Look-Back strategy the following were among the possible actions that might be appropriate:*
>
> *a. establish a task force.*
>
> *b. use nurses with epidemiological research experience or infection control nurses to look at hospital records.*
>
> *c. approach Medical Directors of Trusts to try to identify medical records more quickly.*
>
> *d. use professional counsellors, suitably briefed, as in the case of CJD/HGH recipients.*
>
> *e. direct referral of patients to liver units for testing and counselling.*
>
> *f. representatives of the BTS to visit/telephone hospitals where there are particular problems.*
>
> *The Committee also felt that hospitals that had not largely completed their programme of identifying patients, should be approached by NBA (or the equivalent in other countries) to inquire what their anticipated timescales were for completion of the patient identification stage of the programme."*

2.119. Dr Metters advised that a further report would be made to Ministers in approximately 6-9 months *"…depending upon the rate of further progress with the Look-Back exercise."* (submission paragraph 19).

2.120. My Private Secretary then responded to Dr Metters on 12 February 1996, stating:

> *"Thank you for your submission of 5 February. PS(H) has noted progress with the Look Back exercise and action taken to address the bottlenecks experienced so far. He does not feel that a meeting is necessary at this stage, but would be grateful if you could continue to keep him in touch with developments."* **[DHSC0002533_119]**

2.121. Thereafter followed a further minute from my Private Secretary to Dr Metters dated 4 March 1996. That response read:

> *"Further to our recent telephone conversation about your submission of 12 February, PS(H) has clarified his views. He agrees that central exhortation to speed up the Look-Back process would be unlikely to achieve much. He is content with the preferred option of continuing the current strategy, whilst improving communication between the BTS*

> *and hospitals where there are particular problems and offering assistance to overcome the bottlenecks.*
>
> *PS(H) does not feel that a meeting at this stage is necessary, but looks forward to receiving a further report in the next 6-9 months."* **[DHSC0002533_152]**

2.122. I cannot recall the conversation with my Private Secretary which resulted in the above minutes to Dr Metters. It may be that following my Private Office's initial response of 12 February 1996, Dr Metters contacted my Private Office to get explicit acceptance from me that I was content with the recommended course of continuing the current strategy, whilst improving communication between the BTS and hospitals where there are particular problems and offering assistance to overcome the bottlenecks.

2.123. The Inquiry asks why in response to Dr Rejman's submissions I thought that *"central exhortation to speed up the Look-Back process would be unlikely to achieve much".* As I have set out above, my response was directed to the finalised submission from Dr Metters not the draft submission from Dr Rejman. More substantively, when my Private Secretary indicated that I *"...agree[d] that central exhortation to speed up the Look-Back process would be unlikely to achieve much"*, this was direct citation of the advice from MSBT as summarised by Dr Metters in the submission (see the passage underlined in the quotation at paragraph 2.117 above). I think it would have been apparent to me from the submission and Annex F that both officials and the expert advisory committee as well as Working Party had looked carefully at the options and did not feel that pressure from the central Department was the answer to improving progress on the exercise. Dr Metters was himself closely involved and he was a highly experienced, effective and senior medical officer. While Dr Metters had given the option of a meeting, the submission read with its annexes was full and detailed and I expect that I would have been satisfied with the recommended course without a meeting, especially given the expert advice that had been given by the MSBT.

2.124. The Inquiry also asks,

> *"...why [I] was "content with the preferred option of continuing the current strategy", given that the strategy "had been slower in achieving its objectives than had been predicted?"*

The Inquiry's question somewhat misquotes from the answer my Private Office gave. The full indication my Private Secretary gave was that I was:

> *"...content with the preferred option of continuing the current* strategy, *whilst improving communication between the BTS and hospitals where there are particular problems and offering assistance to overcome the bottlenecks" (emphasis added)*

Neither Dr Metters' submission nor my response suggested that the exercise should continue with the current strategy without any change at all. The recommendation which I accepted was to continue with the current strategy but with the improvements set out in paragraph 12 of Dr Metters' submission. This was to be contrasted with considered other options, including shutting down the exercise and testing all those transfused. A further consideration was that the submission referenced the MSBT as accepting that if all of the bottlenecks were overcome, it was likely that the hepatology services would likely not be able to cope (see paragraph 11 of the submission set out at paragraph 2.116 above.

2.125. I am asked what steps were in fact taken towards *"improving communication between the BTS and hospitals where there are particular problems and offering assistance to overcome the bottlenecks"*. That level of detail would have been for the Working Party and Officials to take forward with the other interested bodies.

2.126. The Inquiry asks whether I received a further report in 6-9 months' time as Dr Metters had indicated would be the case depending upon the rate of further progress with the exercise. The Lookback exercise was referred to in Annex A of the submission sent to us on 23 December and attached to my note to the Secretary of State of 23 January 1997 **[DHSC0004203_013]** (Annex A pages 6-9). This noted that:

> *The "Lookback" of blood transfusion recipients infected with hepatitis C prior to the introduction of screening blood for Hepatitis C in September 1991 has created further pressure. It is likely that approximately 3000 recipients of infected blood who are still alive are*

> *likely to be identified by this exercise, and they are currently being traced. Ministers have given assurances that these patients will be tested and, if appropriate treated[1]. There have been criticisms over the slow progress with the Lookback. Ministers decided not to speed up detection as the bottleneck would then transfer to hepatology clinics. A list of Ministerial and Departmental commitments on the Lookback is available if required, some of which could be interpreted in a wider context.*
>
> *Footnote 1 Interim Report on the Hepatitis C Look Back Exercise submitted to Ministers on 5th February available on request."*

This was not however a full update on progress of the exercise. From the available papers, I have not seen such an update and I do not feel that I can helpfully address from personal knowledge why a further update was not provided, although I note that this was said to be dependent upon the rate of further progress with the exercise.

Section 3. Funding of the AHOs

3.1. I am asked to provide my understanding of the process by which funding allocations were set for the AHOs and what involvement I had in my role as Parliamentary Under-Secretary of State for Health. I am particularly asked about the rationale for providing the Macfarlane Trust with lump sum top ups rather than an annual allocation.

3.2. Both the Macfarlane Trust and Eileen Trust were set up prior to my taking office. I do not recall being asked to review the structure of their funding arrangements or indeed that there was any particular problem with those structures. My knowledge of the AHOs funding arrangements was limited to the information provided to me by my officials and therefore the original rationale for providing the Macfarlane Trust with lump sums rather than an annual allocation is outside of my direct knowledge.

3.3. I do not have any independent recollection of submissions regarding the AHOs. I have therefore reviewed the documents made available to me by the Inquiry and the Department and I provide my comment on them in this statement.

3.4. On 13 February 1996, Mr Guinness put a submission to my Private Secretary which recommended a top up of £2.5 million for the Macfarlane Trust's funds. **[DHSC0004481_013]**. Mr Guinness sets out that:

> *"3. The Macfarlane Trust, an independent charitable trust, was set up in 1987 to make payments to haemophiliacs infected with HIV through blood products and their families who were in need of assistance. Registered individuals receive monthly payments, depending on their individual circumstances. The Trust also makes specific one off grants to individuals in particular need, eg to assist with housing difficulties, mobility needs, respite care and convalescence*
>
> *4…*

> *5. The administrative costs of the Macfarlane Trust have been met by section 64 General Scheme core grants, so that the whole of the capital sum is available for the needs of the client group."*

3.5. The submission continued by confirming that funding for the Macfarlane Trust at that point in time stood at a total of £15 million, consisting of £10 million in 1987 when it was initially set up with a further top up payment having been made in March 1993 of £5 million. At §7 of the submission I was told that *"Ministers have given assurances to the Trust that the Government will "continue to keep the amounts available under review"."*

3.6. I was invited to agree to the proposal that:

> *"(i) the Trust fund should be increased;*
>
> *(ii) £2.5m would be sufficient to ensure the Trust's confidence in its continuing ability to meet need and in the Government's commitment to it;*
>
> *(iii) this expenditure should be met from in-year underspends on the CFS [Centrally Funded Service] programme."*

3.7. My Private Secretary minuted Mr Guinness on 22 February 1996, requesting further information on the proposed payment:

> *"PS(H) has asked for further details before taking a decision on this issue. He is surprised that amounts as large as £2.5m can be afforded from in-year savings and would particularly like to know:*
>
> *What percentage does this represent of total in-year savings from centrally financed services?*
>
> *What plans are there to distribute such in-year savings to other charitable bodies?*
>
> *Why should the Macfarlane trust receive such a large top-up when there are other organisations currently receiving very small grants from DH who are desperate for further funds?"* [**DHSC0004481_012**]

3.8. Mr Guinness responded on 28 February 1996, setting out that:

> *"Against a total cash limited budget of £268 million, the January review produced a total of £7.5 million available for reallocation within the CFS programme."* **[DHSC0004481_011]**

3.9. Mr Guinness further explained the context of the Macfarlane Trust:

> *"5. I think that a distinction has to be drawn between the Macfarlane Trust and organisations receiving grants from DH. The Trust was set up as part of the out of court settlement of the legal action being taken against the Department by haemophiliacs infected with HIV. It is therefore "Government money" being administered by an independent Trust. The Trustees invest the money, and make use of both capital and income to make payments to people registered with it. The Trust started off with £10 million in 1987, and received a £5million top up in 1993. The Trustees feel that, if the balance falls below £4 million, they would be unsure about their ability to fund ongoing payments. While at present their balance is over £5 million, given the current level of payments it would fall to £4 million well before the end of the next financial year. Trustees would undoubtedly then repeat their request for additional funds with added urgency, and there can be no guarantee that the necessary funds would be available at that time. Failing additional funding, the Trustees would have to consider reducing payment levels, and would no doubt make it clear that the reason was that the Government was failing, in their view, to provide adequate funding."* **[DHSC0004481_011]**

3.10. Having received the explanation from Mr Guinness I was happy to approve the payment. With my background in economics I surmise from reading the exchange now that I would have wanted to thoroughly understand the figures and the contextual situation with the Macfarlane Trust, before approving these payments for the first time **[DHSC0004481_010]**. My request for further information was not because I doubted the need for further Macfarlane Trust funding. However, as the minute from my Private Secretary reflects I was surprised that amounts as large as £2.5m could be found from CFS underspends and I wanted re-assurance that we would not be opening ourselves up to criticism of unfair treatment if so much of this was being directed towards the Macfarlane Trust. As the records show, once I had received Mr Guinness's further explanation of 28 February, I was content.

3.11. I am specifically asked to what extent the Government considered representations made by the relevant AHO when setting the financial allocations and whether I considered that the Macfarlane Trust was underfunded during my time as Parliamentary Under Secretary. I am also asked what more could have been done by the Macfarlane Trust to increase their allocation from the Department.

3.12. I do not have any independent recollection of this. But considering the documents now I think it is reasonable to assume from the above statement that Department officials discussed the Macfarlane Trust's financial needs before suggesting the specific top-up figure. I certainly would have read it to have meant that at the time. I was given no indication that the Macfarlane Trust was underfunded in this briefing or any other that I can recall during my time in the Department. If the Macfarlane Trust had considered that the £2.5 million was insufficient, I would have expected them to communicate that to the Department (whether in discussions with officials or in correspondence to Ministers).

3.13. On 8 March 1996, the Rev'd Tanner wrote to me to thank the Department for the confirmation of the top up funds and its continued support of the Macfarlane Trust. There is no indication that the top up funds were insufficient to meet the trusts' needs. On the contrary, his letter stated:

> *"Our work has been much helped by the close interest and support given since the inception of the Trust both by Ministers and officials at all levels of the Department of Health and we thank you for this moral support as well as for the financial grants."* **[MACF0000081_025]**

3.14. I do not recall the funding arrangements from independent memory but I have seen documents pertaining to Section 64 grant funding in the papers made available to me in drafting this statement. The detailed mechanics of the Section 64 grant funding would not have been something I was aware of at the time but I have now seen internal submissions between my officials that it may be helpful to the Inquiry to relate below.

3.15. I have discussed the Haemophilia Society's project grant at paragraph 2.107 above. A minute from Mr Guinness to Mr Orton dated 15 November 1996 discussed bids for increased allocations for CA OPU for the 1997/1998 year

[DHSC0006290_174]. As well as the funding of the Haemophilia Society, these included funding of £177,000 for the administrative costs of running the Macfarlane Trust:

"Haemophilia Society – core grant		*140*
- Project grant		*60*
Macfarlane Trust – core grant		*177*
Eileen Trust – core grant		*22.5*
Council for Music in Hospitals	*.25*	
Arts for Health	*.25*	
Total	*449.5*	
Proposed allocation (min of 11/11)	*400*	
Shortfall	*49.5"*	

3.16. The minute referred to above was seeking ways of increasing CAOPU's allocation to meet the £49,000 shortfall.

3.17. A further internal minute which I would not have had sight of dated 15 November 1996 stated that, in relation to a proposed grant of £100,000 to the Haemophilia Society that this would need to be approved by Ministers. **[DHSC0002570_014]**.

3.18. As I have mentioned in the context of the Haemophilia Society funding, I approved the request and OPU bids for that year by a minute dated 3 January 1997 from my Private Secretary to Mr Guinness **[WIT5294017]**.

3.19. The question around what more the Macfarlane Trust could have done to have increased their allocation from the Department is a hypothetical one because so far as I can tell they did not seek a higher allocation beyond the kind of top up funding that was required. For this top up funding, the funds had to be found from in year savings from the Department budget holders. Additional funding inevitably had to be found amongst the many other calls for health spending. So far as I can tell from the papers, the funding top up being provided was to enable ongoing support at the kind of levels that had been provided previously. Had it been made, a call for markedly increased levels of support from the discretionary payments part of the Macfarlane Trust would have had to have been judged on its merit but also against the other spending pressures of the Department. However, I have not seen anything to suggest that such a case beyond a request for top up funding, was made while I was in post.

3.20. I do not recall any particular issues about the funding arrangements for the Eileen Trust. An increase of its funding does not seem to have been raised with me in a submission while I was the Minister save via the general Section 64 bids I refer to above.

Section 4: INQUIRIES AND REVIEWS

4.1. I have been asked what consideration I gave during my time in office, for calls for a public inquiry. I cannot specifically recall any calls for the establishment of a public inquiry. In my short time in office, my focus on this issue was at considering whether a financial payment scheme was a realistic option, given the monetary and political constraints in play at the time. I was also looking at ways to improve the position of those infected with Hepatitis C and HIV, noting that Baroness Cumberlege, as Parliamentary Under Secretary of State for Health in the Lords, had overall responsibility for dealing with HIV and Hepatitis C as a policy area.

4.2. I can see from the documents available to me that John Marshall did raise the issue of whether a public inquiry was appropriate in his meeting with the Secretary of State on 24 April 1996. The meeting note reports Mr Marshall's comments at §1-2:

> *"Although it was not clear whether he had the full support of the Haemophilia Society for his proposals, Mr Marshall suggested setting up an inquiry into the situation to report in, say, 12 months time…Mr Marshall decided not to pursue the question of an independent inquiry or tribunal"."* **[DHSC0042289_144]**

4.3. There may have been limited calls for a public inquiry at the time and some other references to it in correspondence. However, my impression was that the overwhelming majority of communications from fellow MPs and the public, as well as the Haemophilia Society was to establish robust treatment for those infected and of course, for the Government to look at a payment scheme.

4.4. As I set out above at paragraph 4.1, my focus was on immediate policy areas. I do not recall and could not comment more widely on why the Government did not establish a public inquiry during my time in office. My understanding is that pressure from the public as well as politically became increasingly persuasive in subsequent years.

4.5. I have been asked whether the establishment and findings of inquiries in other countries impacted on the Government's decision not to hold a full public inquiry during my time in office. I am specifically referred to inquiries in Canada, France and Japan.

4.6. I now understand that these countries established inquiries, in accordance with their own jurisdictional rules respectively in 1993 and 1996. I cannot recall whether this impacted on Government policy and its considerations on whether to hold a public inquiry at that particular time.

4.7. As a general point I would stress that whilst the Department would look at action in other countries, and indeed we did look into John Marshall's suggestion in relation to US pharmaceutical companies making payments to those infected, the health systems in those countries referred to at paragraph 4.5 were different to the UK and not necessarily directly applicable.

4.8. I am specifically referred to Lord Norman Fowler's evidence that the government should have established a UK-wide public inquiry before now **[INQY1000144]**, **[INQY1000145]**. There can be no doubt that if a statutory public inquiry is justified, it is best carried out as soon as practicable. That is so because the quality of the evidence will no doubt be better and less voluminous. Those asked to give evidence will be able to recollect more from independent memory and there will be better access to contemporaneous documents. Early investigation no doubt benefits those seeking answers.

Section 5: OTHER ISSUES

5.1. I have been asked to reflect on how the Department, the Treasury and the Government addressed the question of providing financial support and/or recompense to people who had been infected with HCV through the use of blood or blood products provided by the NHS. I think both the departments considered the issues sympathetically and responsibly.

5.2. I am only able to properly comment in relation to my time in office but I have no criticism of those departments. The Department, as I have described in detail at paragraphs 2.15 – 2.103, considered a form of payment scheme for those infected with Hepatitis C. At any time and in relation to any large public expenditure initiative there is a difficult balancing act to be made between different calls on the finite resources available for patient care within the NHS budget. A full compensation scheme was difficult to justify against the background of advice that there had been no fault or negligence by the NHS. However, as I have alluded in paragraph 2.96 above, the strong assessment about the risks of setting a precedent of no fault compensation were too pessimistic. This is the issue which dogged the problem in my time.

5.3. I have been asked to set out my recollection of the reason why it was stipulated that those who accepted the HIV settlement could not go on to sue for being infected by HCV, when that decision was made and by whom. I have been referred to Minutes of the Sixth Meeting of the UK Regional Haemophilia Centre Directors Committee of 16 September 1991 **[HCDO0000441]**. Under item 11a, these minutes illustrate what the waiver was, (“*Patients who accepted the settlement could not go on to sue for becoming infected with HCV*”). But these minutes long pre-date my time as a Health Minister. I was not involved at all with the HIV Litigation settlement and I therefore cannot offer any further comment from my own personal knowledge above the waiver.

5.4. I have no further comments to make in relation to the Inquiry generally, save that I very much hope that the Inquiry, and subsequent report, provides answers to those impacted by what is one of the worst public health tragedies in our living memory. I remain extremely sympathetic to the plight of those who were infected with HIV and Hepatitis C as a result of receiving blood and blood products through NHS treatment.

Statement of Truth

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

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

Dated... 13 May 2022 ...