Witness Name: Stephen James Dorrell
Statement No.: WITN5290001
Exhibits: WITN5290002-WITN529041
Dated: 15/12/2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEPHEN DORRELL

I, Stephen Dorrell, will say as follows: -

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Section 0: Opening Comments

0.1. My name is Stephen James Dorrell. My date of birth and address are known to the Inquiry. I provide this statement to the Inquiry in response to a Rule 9 request dated 5 October 2022, and a supplementary request dated 3 November 2022. I was Parliamentary Under-Secretary of State for Health between 4 May 1990 to 14 April 1992 and the Secretary of State for Health between 5 July 1995 to 1 May 1997.

0.2. I have followed the section headings as they appear in the Inquiry's request and provided my responses under each section heading.

0.3. I would like to begin my witness statement by making a few brief opening comments. The Inquiry will be well aware that the events in which it is interested happened some time ago with the result that my memory of the details is obviously limited. I do however remember well the time and effort which was devoted by both ministers and officials to trying to find ways to help people whose lives had been irreparably damaged by treatments they received in good faith from NHS staff who were trying to help them. I believe the record shows that we tried hard to find ways to help but it also reminded me of the hard truth faced by successive generations of ministers and officials that some dilemmas are irreconcilable and that their job is to accept responsibility for choices which satisfy no-one. I continue to feel the deepest sympathy for those who received transfusions of infected blood and infected blood products, and wish we could have done more to help but the bleak truth is that re-reading the papers simply confirms the view I held at the time that there was no right answer to the questions we faced. I wish it were otherwise.

0.4. Given that the events relevant to the Inquiry took place over 25 years 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 have been asked to set out my professional qualifications relevant to the duties I discharged as Secretary of State for Health between 5 July 1995 and 1 May 1997. I graduated with a Law degree and did not therefore have any qualifications which were specifically relevant to the role of Secretary of State for Health.

Employment History

1.2. I have also been asked to outline my employment history including various roles and responsibilities I have held throughout my career as well as the dates.

1.3. The following table outlines my employment history prior to the appointments in Government detailed below:

Table 1 – Employment History

Date	
1974 to 1979	I worked full time in my family's textile business before entering Parliament in 1979. I remained involved in the business as a non-executive director until I joined the government on 4 May 1990. Thereafter I remained a shareholder of the business but had no outside employment interests until I left office on 1 May 1997.

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

(a) 11 June 1997 - 2 June 1998: Shadow Secretary of State for Education;

(b) 5 July 1995 - 1 May 1997: Secretary of State for Health;

(c) **20 July 1994 - 4 July 1995: Secretary of State for National Heritage;**

(d) **14 April 1992 - 19 July 1994: Financial Secretary (HM Treasury);**

(e) **4 May 1990 - 14 April 1992: Parliamentary Under-Secretary of State (Department of Health);**

(f) **20 December 1988 - 3 May 1990: Lord Commissioner (HM Treasury) (Whip);**

(g) **26 June 1987 - 19 December 1988: Assistant Whip (HM Treasury).**

1.5. My parliamentary committee memberships include:

(a) 3 May 1979 - 9 June 1983: Transport Committee.

(b) 27 April 1992 - 18 October 1994: Public Accounts Committee.

(c) 14 November 2005 - 6 May 2010: Consolidation etc. Bills (Joint Committee).

(d) 10 June 2010 - 4 June 2014: Chaired the Health and Social Care Committee.

(e) 10 June 2010 - 4 June 2014: Health and Social Care Committee.

(f) 19 July 2010 - 4 June 2014: Liaison Committee (Commons).

(g) 6 December 2010 - 30 March 2015: Consolidation, &c., Bills (Joint Committee).

Ministers in post during my tenure

1.6. While I was in post as Secretary of State for Health, the relevant Ministers, and Parliamentary Under Secretaries were as follows: -

(1) Minister of State:

(i) Gerald Malone was the Minister of State for Health (20 July 1994 – 1 May 1997)

(2) Parliamentary Under-Secretaries:

The Parliamentary Under-Secretaries for Health were the Parliamentary Under-Secretary of State in the Lords and the Parliamentary Under-Secretary of State for Health:

(i) The Parliamentary Under-Secretary of State in the Lords was Baroness Cumberledge (14 April 1992 – 2 May 1997).

(ii) The Parliamentary Under-Secretary for Health was:

   i. Thomas Sackville (10 April 1992 - 29 November 1995)

   ii. John (now) Lord Horam (29 November 1995 -1 May 1997)

(3) Permanent Secretary

Throughout my tenure, Sir Graham Hart was the Permanent Secretary (2 March 1992 - 30 November 1997).

Responsibilities as Parliamentary Under Secretary of State for Health and Secretary of State for Health

1.7. I have been asked to describe my responsibilities as Parliamentary Under-Secretary (PUSS) of State for Health and Secretary of State (SoS) for Health, in so far as they are relevant to the Inquiry's Terms of Reference.

1.8. My involvement with blood issues during my time as PUSS was limited. It is possible in this role I may have responded to some PQ's or correspondence on the subject matter, but I have no direct recollection of this. William Waldegrave became Secretary of State for Health on 2 November 1990 and on review of the documents, I can see that on 5 December 1991 William Waldegrave sought my view, as well as that of other Ministers, on the extension of the payments scheme to those infected through blood transfusions [DHSC0002537_063]; [DHSC0002537_062]; [DHSC0002537_262].

1.9. On 11 December 1991, my Assistant Private Secretary (APS), Helen Bloomfield, responded as follows, [DHSC0002537_242]

> *"PS(H) has seen your minute of 5 December, asking for his views on Permanent Secretary's minute of 2 December. He has commented "Without enthusiasm I am in favour of extending the concession to Blood Transfusion etc., victims. The initial concession was a political fix - this would simply redefine what is essentially the same fix."*

1.10. Following my appointment as Secretary of State on 5 July 1995 I was responsible for all the activities of the Department of Health. I was supported in my responsibilities affecting infected blood by officials whose departmental reporting line fed through the Permanent Secretary, Sir Graham Hart, and by ministerial colleagues – Tom Sackville MP until 29 November 1995 and thereafter John Horam. I believe the record shows that ministers and officials worked closely during my period as Secretary of State to understand the implications of the policy options available to the Government, to reach conclusions on the basis of that understanding, and to explain them to MPs and their constituents who raised concerns about them.

1.11. Paragraph 1.9, above, shows that as PS(H) I had suggested to William Waldegrave "without enthusiasm" that there was a case for extending the scope of the payments which had already been granted to patients who had been infected with HIV through blood products, to those infected with HIV through blood transfusions. We did not at that time (1991/1992), or indeed during my time as Secretary of State, make a further extension to those infected with HCV via blood products or blood transfusions, although the record shows we considered this option extensively during my time as Secretary of State. We did not follow up this option for reasons which are set out in detail in this witness statement. In particular I have set out in this statement the strong concerns about the slippery slope towards no fault compensation. On the extension of the HIV scheme to transfusion patients, however, I think that my reference to there having been a 'political fix' simply relates to the fact that an exception had been made for those infected with HIV through blood products, and the extension to HIV through blood transfusion being suggested in December 1991 (and announced shortly afterwards) was only a re-drawing of the exception to include other routes of transmission of HIV.

1.12. While I return to some of these points in my statement below, in summary I would say that:

a) At a human level there was obviously deep sympathy for the predicament of all individuals who lives were damaged by these actions;

b) Ministers had agreed to make payments to patients infected with HIV and had justified these payments on the basis that the life expectancy of the individuals concerned was severely curtailed and public and political opinion was particularly sympathetic to their predicament;

c) Ministers recognized from the beginning that these payments created an awkward precedent and others whose lives had been damaged by clinical interventions conducted in accordance with contemporary best practice would probably claim that their circumstances justified similar payments;

d) The Government was however committed to the view that the priority for the use of NHS resources needed to be the provision of future NHS care in accordance with current best practice and that resources committed to discretionary payments to individuals whose lives had been damaged by care delivered in accordance with contemporary best practice ran the risk of undermining that priority;

e) Ministers were therefore open to discussions which reflected the reality that, for a limited number of individuals, NHS care had had a damaging effect on their lives, but believed these discussions needed to take place against the background of their desire to avoid an extension of the "special case" status which had been accorded to those who were infected with HIV by NHS blood products or blood transfusions.

Evidence to other inquiries, investigations or criminal or civil Litigation

1.13. I have not given 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. However, I gave two written statements to the BSE Inquiry in relation to my time as Parliamentary Under Secretary of State for Health and Secretary of State for Health [WITN5290002]; [WITN5290003]. I gave oral evidence to the Inquiry on 26 November 1998 [WITN5290004].

Section 2: My time as Secretary of State for Health

Calls for a payment scheme

2.1. I have been asked to set out the reasons for resisting calls for a payment scheme for those infected with HCV from blood and blood products during my tenure as Secretary of State for Health (SoS) and the rationale for refusing these calls when those who had been infected with HIV had received payments.

2.2. I can confirm I have reviewed the following documents to assist in answering this question, referred to me by the Inquiry:

1) Extract of the evidence I gave to the Health Committee (Public Expenditure Enquiry) dated 19 July 1995 [DHSC0042937_094];
2) Letter from a constituent to the Rt Hon John Major MP re: support and financial help for those with Hepatitis C dated 18 January 1996 (pages 10-11) [HSOC0000144];
3) Draft Paper of a final version sent on 9 February 1996, from Mr Guinness to PS(H)'s Private Secretary, Marguerite Weatherseed, re: Compensation for Haemophiliacs with Hepatitis C undated [DHSC0042937_014];
4) Note of Meeting with John Marshall MP to discuss compensation for haemophiliacs with hepatitis C, attended by me, Mr Holden and Mr Pudlo, dated 15 April 1996 [DHSC0041255_074];
5) Minute from Paul Pudlo to my Private Secretary, re: compensation for haemophiliacs – meeting with John Marshall MP dated 1 May 1996 [DHSC0003883_089];
6) Minute from Paul Pudlo to my Private Secretary, re: compensation for haemophiliacs – meeting with John Marshall MP, containing additional information dated 10 May 1996 [DHSC0042289_107].
7) Letter from member of the public to Rt. Hon Sir John Stanley re: support for haemophiliacs and Conservative party policy on haemophiliacs and funding undated [DHSC0046935_240];

8) Letter from the Rt. Hon Sir John Stanley MP to me, attaching the letter [DHSC0046935_240], and requesting a response to points raised, dated 21 November 1996 [DHSC0046935_239];

9) Response from me to the Rt Hon Sir John Stanley MP's letter [DHSC0046935_239] dated 2 December 1996 [DHSC0046935_238];

10) Letter from Andrew Smith MP to me re: request for evaluation of the government's position on compensation for victims of Hepatitis C infected by blood dated 12 December 1996 [DHSC0046935_132];

11) Letter from Rt Hon Michael Morris MP to me re: Hepatitis C Compensation – Factor 8 dated 12 December 1996 [DHSC0046935_152];

12) Letter from John Watts MP to me re: request for comments regarding the difference in compensation in HIV and Hepatitis C dated 20 December 1996 [DHSC0046935_094];

13) Letter from John Horam to Andrew Smith MP re: rejection of financial compensation to haemophiliacs who have been infected with hepatitis C dated 3 January 1997 [DHSC0046935_131];

14) Letter from me to the Rt. Hon Michael Morris MP re: rejection of financial compensation to haemophiliacs who have been infected with hepatitis C dated 13 January 1997 [DHSC0046935_151].

2.3. For the benefit of the Inquiry, I set out a chronology on how the discussion over a payment scheme developed during my time as SoS. The Inquiry will be aware that whilst I was SoS for Health a payment scheme was not set up for those who had contracted HCV through blood and blood products.

2.4. In July 1995, I was appointed SoS for Health taking over from Virginia Bottomley. Discussions over a payment scheme for Haemophiliacs who had contracted HCV through blood/blood products had already taken place before I took up the post. Although I was not aware of the detail of these discussions before July 1995, I was well aware of the Government's position on the principle of no-fault compensation, and I would have been provided with detailed briefing on the background as part of the briefing prepared by officials for a newly appointed minister.

2.5. On 3 July 1995, two days before I took up post, Paul Pudlo, a policy official, emailed Mr Holden, Private Secretary to the SoS, headed '*HCV – INFECTION FROM BLOOD/BLOOD PRODUCTS*' [WITN5289031]. The previous SoS was clearly involved in considerations of a compensation scheme, and I inherited this issue as part of my portfolio. Mr Pudlo wrote:

> *"At the meeting on 21 June to discuss the case for and against compensation SofS asked for a summary of the current positon (sic) on a number of issues.*
>
> *The attached note draws material from a number of submissions and comments from some copyess (sic) under the headings mentioned at the meeting Others have been added to fill in the gaps. I'm afraid the complexity of the issue has meant that this is longer than was hoped." [WITN5289031]; [WITN5290005].*

2.6. There is a version of this submission which has handwritten annotations, "*P[rivate] O[ffice] rang 5/7 SoS has seen + noted "No further action needed at present*", [DHSC0002549_108]. As this was the time I was coming into office and Virginia Bottomley was leaving, it is not clear if the notes recorded my view or that of Virginia Bottomley.

2.7. On 11 July 1995, a Parliamentary debate took place. I don't recall attending this debate and it is unlikely that I would have done so. It was an adjournment debate raised by John Marshall on the issue of a payment scheme and Tom Sackville was Parliamentary Under-Secretary of State for Health, replied on behalf of the Government [WITN5290006].

2.8. In the debate, Tom Sackville, responded to Mr Marshall setting out the position of the Government in the following terms:

> *"Let us look at the facts of hepatitis C. Most haemophilia patients infected with hepatitis C were so infected before blood products were treated to destroy viruses in 1985. That was well before the first hepatitis C tests were available in 1989. Those patients received the best treatment available in the light of medical knowledge at the time. When those patients were infected, little was known about hepatitis C, or non-A, non-B hepatitis as it was then known, and even today a lot more information is needed.*
>
> ……..
>
> *No one should underestimate the effects of hepatitis C. The point that I am making, and this is at the heart of the debate, is that contrary to views that have already been expressed in another place, patients who tragically contracted HIV through NHS treatment were in a different category. Their exceptional circumstances caused us to make special provision for them.*
>
> *Many people infected with hepatitis C, as has already been said by my hon. Friend, may live for a long period without any symptoms appearing. However, 50 per cent. of sufferers may progress to chronic hepatitis with varying degrees of good or ill health. Perhaps 20 per cent. of infected patients will develop cirrhosis, a progressive destruction of the liver that may take 20 to 30 years. The majority of those years will be trouble-free in terms of ill health and, as I have mentioned, only a small proportion will die of liver disease, but every death is a tragedy for the family concerned.*
>
> *In the case of those who contracted HIV through NHS treatment, special payments were made and trusts established to help sufferers or their families in cases of hardship. Those arrangements were put in place in recognition of the very special circumstances of those who contracted HIV. Those affected were all expected to die very shortly, although it has*

since become clear that, fortunately, that is not always the case. It meant that there might also be significant numbers of young children who had lost one parent or perhaps both if the disease had been transmitted also to their partner.

Sufferers were also subjected to stigmatism and a whole range of other social problems. There were cases of doors daubed with graffiti, lost jobs and children not allowed to mix with other children at school-in short, people were denied any normal family life.

I would in no way wish to minimise the physical suffering of those who have been infected with hepatitis C through blood or blood products-the suffering which may result or the worry which they or their family may experience-but each case has to be examined on its merits. I have to recognise that those who have contracted hepatitis Care not also subject to all the additional problems experienced by HIV sufferers, who were accepted as being a very special case.

Many people infected with hepatitis C may live for a long period without any symptoms appearing or may never experience any. In any case, some people would argue that although individuals were infected in different ways, they are entitled to payments-even though no fault on the part of the NHS was proved. The Government have never accepted the case for a no-fault scheme of compensation for medical accidents. There are sound reasons. Proof of causation would still be needed. It may be just as difficult to establish that medical treatment has caused injury as to prove that someone has been negligent. It also has to be demonstrated that the outcome was not a foreseeable and reasonable result of treatment.

> *It would be unfair to others if individuals whose plight was the result of a medical accident would be compensated, whereas those whose condition stemmed, for instance, from disease from birth would not. Health negligence is not considered fundamentally different from negligence in other walks of life, where claims for compensation are*
>
> *resolved through the courts.*
>
> ……….
>
> *The Department is already supporting an initiative by the Haemophilia Society to undertake a study of the best way to support those of its members who are infected with hepatitis C. The Department has made available substantial funding in 1995 and 1996, with a commitment to further funding over a number of years. We are also discussing with haemophilia centres what must be done to ensure good practice in the treatment of people with haemophilia who also have hepatitis C.*
>
> *If I may, I shall summarise what I have said. On behalf of the Government, I would like to express the greatest sympathy for those who have contracted hepatitis C through NHS treatment. We are taking a number of measures designed to enable them to receive the best possible advice and treatment. But it remains the Government's view that, in the absence of proven negligence on the part of the NHS, there is no case for using moneys which would otherwise*
>
> *be used for the care and treatment of other NHS patients to make special payments to those affected."*

2.9. On 18 July 1995 Graham Barker from the Haemophilia Society wrote to Mr Pudlo referring to letters members had received from Tom Sackville [DHSC0002474_005]:

> *"… the Health Departments are considering a range of potential initiatives to improve the understanding, treatment and management of hepatitis C. On 11 July, in the House of Commons Mr Sackville said (Hansard 11.7.95*

> *column 862): "We are taking a number of measures designed to enable them (those who contracted hepatitis C through NHS treatment) to receive the best possible advice and treatment."*
>
> *I would be grateful if you could explain in some detail what these measures are."*

2.10. On 19 July 1995 I gave evidence before the Health Committee (Public Expenditure Inquiry) [DHSC0042937_094]. I was sent a copy of the extract of my evidence on 28 July 1995 as all attendees were asked to review the extract for factual accuracy [WITN5290007].

2.11. On 31 July 1995 I wrote to Sir Edward Heath MP [DHSC0032176_003]. I was responding to his recent letter enclosing correspondence from a member of the public about the Haemophilia Society's campaign on behalf of patients with haemophilia who contracted HCV. I responded in the following terms:

> *"As Tom Sackville said in the adjournment debate on 11 July, the Government has great sympathy with those patients who may have become infected with hepatitis C through blood transfusions or blood products.*
>
> *Most haemophilia patients were infected with hepatitis C before blood products were treated to destroy viruses. These patients received the best treatment available in the light of medical knowledge at the time.*
>
> *The Health Departments are considering a range of potential initiatives to improve the understanding, treatment and management of hepatitis. This could include encouragement of research into the condition and guidance to the NHS on best practice where there is a clinical consensus.*

> *The Government does not accept, however, that there has been negligence and we have no plans to make payments to such patients. On the more general issue of compensation, the Government has never accepted the case for a no fault scheme of compensation for medical accidents. It is unfair to others and still requires proof of causation which is often difficult to establish. Every individual case where a medical accident has occurred is a personal tragedy for both the individual concerned and their family. If the NHS is proved negligent in a Court, it accepts its liability to pay damages.*
>
> *It is the Government's view that the most effective use of resources is to seek to improve the understanding, management and treatment of the condition. Only in this way can the impact of the disease on individual patients and their families be effectively minimised.*
>
> *This Department is already supporting an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with hepatitis C, and has made available*
>
> *£91,000 in 1995/96, with a commitment to further funding in 1996/97 and 1997/98 for this purpose.*
>
> *I hope that this will reassure you that the Government will do all it can to care for those affected."*

2.12. This letter was drafted by policy officials; the fact that it was addressed to a former Prime Minister who I knew well and was commenting on an issue which was clearly the subject of current political debate would have meant that I considered the contents carefully before signing the letter. The letter therefore reflected the Department's established position at the time and provided me with an opportunity to clarify my own view early in my tenure as Secretary of State.

2.13. On 2 August 1995 Tom Sackville responded to a letter from the Manor House Group [DHSC0020838_198]. In the response he stated:

> *"I explained in the Adjournment Debate, on 11 July, the Government's view that, despite our sympathy for those who have contracted Hepatitis C through blood or blood products, in the absence of proven negligence there is no case for using monies which would otherwise be used for the care and treatment of other NHS patients to make special payments to those affected. While your letter mentions an out of court settlement, the only cases involving Hepatitis C we are aware of have been restricted to instances involving local health authorities where clinical negligence has been proved. As I have said, we do not accept that this is the case in relation to all haemophiliacs generally. It remains our view that the most effective use of available resources is to seek to improve the understanding, management and treatment of the condition. For instance, discussions are taking place between the Department and the Directors of the Haemophilia Centres about what needs to be done to develop good practice for the treatment of people with haemophilia who are also HCV positive and to ensure that such people have access to treatment centres. The Department is already supporting an initiative by the Haemophilia Society to undertake research into the best way to support its members who are infected with HCV. The Department is also giving sympathetic consideration to appropriate requests for support from any self-help groups which might be able to provide cost-effective assistance to their members.*
>
> *As I promised during the adjournment debate, the Department will in particular took into the question of the provision of alpha interferon for treatment of patients infected with hepatitis C and officials are already in contact with the Haemophilia Society to obtain further information. We are also considering other steps which could be taken to ensure that any additional research which might be required to improve the understanding, treatment and management of those affected is undertaken."*

2.14. The Rt Hon Roy Hattersley wrote to me on 22 August 1995 enclosing a constituent letter [DHSC0003552_042]. I responded on 19 September 1995 [DHSC0003552_041]. On 26 September 1995 I received a reply from the Rt Hon Roy Hattersley MP who stated, [WITN5290008]:

> *"I hope you will forgive me writing to you in very frank terms. You replied to my letter of the 22nd August - concerning haemophilia sufferers who had contracted the hepatitis C virus as a result of medical treatment - with what was clearly a standard letter. You must know that sentences like "I am sorry to read that Mr* GRO-A *suffers from haemophilia . " and "I hope that this will reassure . . . " are more inclined to antagonise than to comfort. Mr* GRO-A *telephoned my office to see if you had replied to my letter and was told that you had. I have therefore no choice other than to send it to him. But it will only add to the anguish.*
>
> *I do not minimise the problems of pressure on your time and I realise therefore the temptation to send out such letters. But they really do more harm than good.*
>
> *May I, in these exceptionally distressing circumstances, ask you if you would agree to see me, together with a couple of representatives from the Manor House Group? I know it will take half an hour of your time, but it would be very worthwhile from every point of view."*

2.15. Mr Hattersley was a former Deputy Leader of the Labour Party and a senior Member of Parliament. I remember being concerned by the tone of his letter and asked my office to ensure that the meeting he requested took place – as it eventually did on 19 December 1995 – see 2.30 below.

2.16. On 27 September 1995, Tom Sackville responded to a letter from Veronica Hardstaff MEP, which had been addressed to Baroness Cumberledge. In the response he explained the difference between HIV and HCV sufferers and why the Government has drawn a distinction between the two groups. In his response he stated, [BNOR0000296]:

> *"At the time the HIV settlement was made, haemophilia patients with HIV were expected to die shortly. Fortunately, with progress in treatment, the numbers who have survived are greater than we expected. However, out of the 1238 haemophilia patients infected with HIV, more than half (641) have progressed to AIDS and died. With respect to hepatitis C, it is believed that the vast majority of haemophilia patients treated with blood products prior to 1985 are infected with the virus i.e. a total of about 4,000 (including the 1238 who are HIS? positive). Our latest figures from the UK Haemophilia Directors Association show that 48 of those patients have died from liver disease up to December 1993, of whom at least 22 were HIV positive; it is known that co-infection with HIV leads to more serious clinical problems with hepatitis C. The long period of time during which haemophilia patients with hepatitis C are able to lead normal lives is also reflected in the ages at which those with HIV have died in comparison with those with hepatitis C. A significant proportion of those with HIV have died whilst still young and with dependent children and have therefore lost many years of potential life. 129 living haemophilia patients with HIV have dependent children, and 153 of the patients who have died had dependent children. Patients with hepatitis C and clinical symptoms, on the other hand, in particular those not co-infected with HTV, have tended to be older and so are less likely to have dependent children. I hope these comments go some way to explaining the difference between HIV and hepatitis C."*

2.17. On 7 November 1995 Graham Barker wrote again to Mr Pudlo chasing a response to his earlier letter dated 18 July 1995 and repeating his request for details of the range of potential initiatives the Government was considering to improve its understanding, treatment and management of hepatitis C [DHSC0041361_046].

2.18. On 16 November 1995 Paul Pudlo responded to Graham Barker stating, [HSOC0003756_003]

> *"I must apologise again for the delay in responding formally to your letter of 18th July. As discussed on the phone this is not because nothing has been happening but partially because of progress chasing and partially the range of branches within the Department that have an interest in Hepatitis C."*

2.19. On 30 November 1995 Paul Pudlo sent an email to Richard Billinge, and other DH officials advising them of the release of the Haemophilia Society's interim report into the impact on its members who had been infected with HCV. Mr Pudlo advised the line should remain [DHSC0004498_141],

> *"The Government has great sympathy for those infected with Hepatitis C as a result of NHS treatment. But as no fault nor negligence on the part of the NHS has been proved there are no plans to make special payments."*

2.20. On 5 December 1995 John Marshall MP asked an oral Parliamentary Question to the SoS, "*what representations he has received about making an ex-gratia payment to haemophiliacs infected with Hepatitis C"* [DHSC0042937_047].

2.21. In addition to the proposed reply to the oral PQ, as was normal practice, a briefing pack was provided which provided fuller context and advice on possible supplementary questions. It also included the briefing provided to the Prime Minister dated 21 November 1995 [WITN5290009]. These briefings were part of the regular process of ensuring that the PM was briefed on current issues ahead of his twice weekly appearances at Prime Minister's Questions; they were therefore the subject of regular scrutiny both ministers and senior officials. The briefing dated 21 November 1995 stated,

> *"<u>HEPATITIS C</u>*
>
> *I have great sympathy with those who may have been inadvertently infected with Hepatitis C through NHS treatment.*

I am confident that the patients concerned received the best treatment available in the light of medical knowledge at the time.

Since 1991. when a reliable test became available, all blood donations have been tested for Hepatitis C to prevent such infection.

Arrangements have been made to trace, counsel and - if necessary - treat those who may have been infected through blood transfusions. The Department of Health is also supporting an initiative by the Haemophilia Society to study the best way of supporting those who are infected with the Hepatitis C virus.

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 i 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."*

2.22. Prime Minister's Questions took place twice a week at that time. Policy officials would send the Prime Minister an update on Tuesdays and Thursdays, and this was the format Sir John Major, PM at the time, liked to have for his briefing. Much of the content of the briefing is along the same lines as the content of my letter referred to in paragraph 2.11 above. This confirms that this was the Government's established position at the time on the subject of a payment scheme for haemophiliacs.

2.23. John Horam (who had taken over as PUSS from Tom Sackville) replied to Mr Marshall's question in the House on 5 December, as follows:

> *"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." [WITN5290010]*

2.24. Also, on 5 December 1995 John Horam responded on my behalf to a letter from Dame Janet Fookes DBE MP, which she had written enclosing a letter from her constituent [WITN5290011]; [WITN5290012]. In his response he said, [DHSC0004498_131]:

> *"The Health Departments are considering a range of potential initiatives to improve the understanding, treatment and management of hepatitis C. This could include encouragement of research into the condition and guidance to the NHS on best practice where there is a clinical consensus."*

2.25. On 7 December 1995 I responded to a letter from the Rt. Hon Alfred Morris AO QSO MP enclosing one from his constituent [WITN5290013]. In my response I mentioned that the Department was, "*…considering a range of potential initiatives to improve the understanding, treatment and management of hepatitis C".* The response also mentioned the UK-wide Look back exercise and said, [DHSC0004498_121]

> *"The Health Departments have announced a UK-wide look back exercise with a view to tracing, counselling and, where appropriate, treating those*

> *who have been put at risk as a result of exposure to the hepatitis C virus through blood transfusion. This work has already been put in hand and will be undertaken as quickly as possible."*

2.26. On 12 December 1995 Ann Towner a policy official, sent briefing to Mr Pudlo and Mr Hillcoat, my diary secretary, for my meeting with Roy Hattersley and the Manor House Group which had been arranged to take place on 19 December 1995 following his request in his letter dated 26 September 1995 [WITN5290014]; [WITN5290015].

2.27. On 13 December 1995 an adjournment debate took place in the House of Commons. Prior to the debate, on 11 December 1995, Paul Pudlo circulated a briefing which was copied to my Principal Private Secretary, Claire Moriarty [DHSC0006774_048]. [The briefing included a background note at Annex C (i) which stated, [WITN5290016]

> ***"Reason for not making payments***
>
> *The Department cannot dispute that some people have been infected through NHS treatment but deny negligence. Although patients received the best treatment available based on existing knowledge it has to be recognised that not all medical interventions are risk free. Risks may be evident at the time of treatment or may be discovered later. If payments were to be offered for each such incident we would soon slip into a general no fault compensation scheme. The Government is opposed to a no-fault scheme, which would be unworkable and unfair.*
>
> ***Comparison with HIV***
>
> *The Government accepted that the patients who, tragically, contracted HIV through NHS treatment were in a different position from others and made provision for them because of their very special circumstances. Those affected were all expected to die very shortly and were subjected to significant social problems, including ostracism. In the case of the*

infected haemophilia patients, the problems of HIV were superimposed on the health, social and financial disadvantages they already suffered as the result of their hereditary haemophilia.

Hepatitis C is different from HIV. Many people infected with Hepatitis C may enjoy a long period without any symptoms appearing. 50% of sufferers may progress to chronic hepatitis with varying degrees of good and ill health. Perhaps 20% of infected patients will develop cirrhosis, a progressive destruction of the liver, that may take 20 to 30 years. The majority of those years will be trouble free in terms of ill health and only a small percentage will actually die of liver disease. Ministers have therefore made clear that they have no plans for a payments scheme.

The Haemophilia Society stated in their original press release that over 40 haemophilia patients have died through infection with hepatitis C virus. (Recent EDMs give the figure now as 50, which does not seem improbable as it presumably includes a figure for 1994.) It is important to retain a clear sense of proportions and timescales. The figure of 40 quoted by the Society related to the 5 year period 1988 to 1993 and this is out of a figure of over 4000 who are positive from hepatitis C (ie 1%). In 1993 12 haemophilia patients died with the cause of death shown as liver disease. This was out of 126 haemophilia patients known to have died in that year. Of these 12, 8 were also HIV positive. Without seeking to minimise the tragedy these are small numbers when weighed in the balance of the good that treatment has brought to many of these and countless others. As a comparison the number of haemophilia patients who have died of AIDS is 619 out of 1238 who are HIV positive (ie 50%).

……..

Departmental action

The Department is supporting 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 year [with agreement in principle to funding for a further 2 years].*
>
> *The Health Departments have mounted a UK wide look back exercise to trace, counsel, and where necessary treat those who may be at risk of hepatitis C through blood transfusion. The start of the exercise was announced on 4 April 1995. Officials will be reporting back to Ministers shortly.*
>
> *DH are considering other steps which could be taken to ensure for example that: treatment is made available and that any additional research which might be required to improve the understanding, treatment and management of those affected be investigated. DH is also giving sympathetic consideration to appropriate requests for support from any self help groups which might be able to provide cost effective assistance to their members."*

2.28. At the debate, John Horam, stated as follows on the subject of a payment scheme [HSOC0002072],

> *"It has been argued that the fact that ex gratia payments were made to those who contracted HIV through blood or blood products means that payments should also be made in the present case. As both the hon. Gentleman and my hon. Friend will be aware, the Government have not accepted that proposal so far. We believe that different prognoses have been made for those with hepatitis C and those with HIV.*
>
> *Many people infected with hepatitis C may live for a long period without any symptoms appearing, and my hon. Friend has conceded that. Fifty per cent. of sufferers may progress to chronic hepatitis with varying degrees of good or ill health. Perhaps 20 per cent. of infected patients will develop cirrhosis-a progressive destruction of the liver-that may take 20 to 30 years to be fully apparent. The majority of those years will be trouble-free in terms of ill health and, as I have mentioned, only a small proportion will die of liver disease.*

> *The Haemophilia Society's report of its hepatitis C impact study makes a valuable contribution to our understanding of the effect of hepatitis C in this situation."*

2.29. Mr Horam went on to say,

> *"My Department is supporting an initiative by the Haemophilia Society to undertake a study of the best way to support its members who are infected with hepatitis C, and has made available substantial funds in 1995-1996 with a commitment to further funding in 1996-1997 and 1997-1998 for this purpose. My Department is also looking at what appropriate research may be undertaken to increase knowledge of hepatitis C, its natural history and its optimal treatment.*
>
> *One example of that is that the standing group on health technology has identified the evaluation of the use of alpha interferon in the treatment of hepatitis C as a top priority in the NHS. Such developments are important to increase the evidence base upon which decisions can be made on the best treatment for each individual patient.*
>
> *It is the Government's view that the most effective use of resources is to seek to improve the understanding, management and treatment of the condition. This is the best way to minimise the impact of the disease- which the hon. Gentleman described so graphically- on individual patients and their families. The Haemophilia Society's recent report gives examples of that."*

2.30. On 18 December 1995 JW Grice from the Treasury wrote to Mr Dobson at the Department of Health following the debate expressing their concern of John Horam's use of the words 'relatively modest and restricted proposal' [DHSC0042937_036]. Although I believe Mr Horam's comment was simply intended to indicate his willingness to consider all options, the Treasury was clearly concerned that Mr Horam, as a relatively newly appointed minister, appeared to be straying from the accepted Government line on a spending issue. The record shows that the Government's position was clear, but the

Treasury was properly concerned that statements by ministers might create the impression that it was being reconsidered. I was fully aware of Mr Horam's desire to review all the available policy options, and he had my full support in doing so, but it is an important discipline within government that these considerations take place without raising expectations which the Government had not agreed to meet. It is this concern which lay behind the intervention of H M Treasury on 19 December 1995.

2.31. On 19 December 1995, I met with Roy Hattersley and the Manor House Group as scheduled [DHSC0003971_075]. Also in attendance was Graham Ross, a Solicitor who had been involved in HIV haemophilia litigation. Following the meeting Mr Pudlo circulated a note of the meeting [WITN5290017] stating,

> *"Much of the hour long meeting was taken up with a series of emotive accounts of individual plight to which SofS listened patiently. It was clear from the outset that it was about money rather than the language of PO replies. The usual issues of access to alpha interferon and recombinant factor VIII were raised to which SofS played the standard line. However he was surprised at allegations that some patients (including GRO-A) had been kept in the dark about Hep C infection for some time after it had been diagnosed. We explained that what a patient is told is a matter for local judgement and that there may be reasons for not informing immediately - eg no treatment available - unreliable tests. SofS asked for GRO-A's case to be investigated.*
>
> *Mr Ross offered SofS a deal that he would call off legal action if SofS shared among the group the money it would save from not having to defend a legal action."*

2.32. I refer the Inquiry to an undated letter from Mrs GRO-A [WITN5290018]. In the letter Mrs GRO-A was thanking me for my time on 19 December and referred to her two sons who both suffered from haemophilia. I believe from the review of the documents that she was one of the attendees at the meeting, to whom Mr

Pudlo refers, gave their account of the impact of HCV on their lives. She goes on to say,

> *"…I know you are a very busy man, this is why I am writing to you, to tell you how much I appreciate the time you very kindly gave me, to listen to my problem I have been experiencing with my boys."*

2.33. Also on 19 December 1995, Graham Barker responded to Paul Pudlo's earlier correspondence stating, [DHSC0002533_050]

> *"I must say that we are disappointed at the slow rate of progress on the issues raised in my letter of 18th July 1995.*
>
> *On 11th July in the House of Commons Mr Sackville said (Hansard column 862).*
>
>> *"We are taking a number of measures designed to enable them (those who contracted hepatitis C through NHS treatment) to receive the best possible advice and treatment."*
>
> *Again on 13th December John Horam said (Hansard column 961).*
>
>> *"It is the Government's view that the most effective use of resources is to seek to improve the understanding, management and treatment of the condition."*
>
> *I would be grateful if you could spell out what action the Government is taking."*

2.34. On 20 December 1995 Ann Towner, a policy official, minuted Paul Pudlo and Mr Horam's Private Secretary at the time, Marguerite Weatherseed, in relation to lines being used in correspondence [DHSC0004498_051]. The minute noted that John wanted to insert the words '*at present*' into the standard wording being used '*we have no plans to make special payments'*. In the minute Ms Towner stated,

> *"In answering recent parliamentary questions and in adjournment debates PS(H) has said that he wishes to study the Haemophilia Society's interim report of its impact study carefully before coming to any conclusions about it implications. He has also indicated a willingness to study any new proposals (eg for schemes limited to those who develop chronic illness). However 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".*

2.35. It appears the policy branch shared the Treasury's concerns and Mr Horam's proposed wording appeared to be softening the Government's established position on the matter. The minute therefore went on to suggest Mr Horam might clear the additional wording with me.

2.36. On the same day Mr Guinness forwarded the minute to the office of the Permanent Secretary, (at the time Sir Graham Hart) stating, [DHSC0004498_188].

> *"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"*

2.37. It appears Mr Horam's private secretary brought this to his attention and replied the next day stating, [DHSC0004498_045]

> *"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."*

2.38. On 21 December 1995, Dr Rejman wrote to Dr Nicholas and Dr Doyle at the Department referring to the meeting [WITN5290019]. He also mentioned that at the meeting Mr Ross had handed a copy of a press release regarding the use of Thymosin and Alpha Interferon for HCV asking them for any comments on the trial and whether researchers in the UK had been involved [[WITN5290020].

2.39. Also, on 21 December 1995 Mr Horam responded on my behalf to the Haemophilia Society's letter sending me a copy of their interim report [DHSC0004498_086]; letter [WITN5290021]:

> *"You will, no doubt, be aware that the report was referred to during the debate in the House of Commons on 6 December. As I said then, I want to give it the attention it clearly merits and I am reading it carefully…*

> *You are familiar with the Government's position on the question of compensation to haemophiliacs who were inadvertently infected. I think it fair to say that it is acknowledged by all concerned that these patients received the best treatment available in the light of medical knowledge at the time and indeed treatment which provided substantial benefits and to which there was no real alternative. I think it is also common ground that there is no question of negligence by the NHS.*
>
> *Our position is founded on the belief that, in the circumstances, tragic as they are, the most effective use of resources nonetheless remains, to seek to improve the understanding, management and treatment of the disease. I outlined to the House a range of measures that we are taking to that end. I hope that I also made it clear that I consider it very important these processes are informed by an understanding of the needs of the patients concerned. In this respect I already have no doubt that your Society's interim report represents a valuable contribution and I look forward to the final version."*

2.40. In this letter, as he did in the debate on 13 December 1995, Mr Horam indicated that he intended to read the Haemophilia Society's report for himself. In the debate, he also said, [HSOC0002072]

> *"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."*

2.41. On 8 January 1996 Kevin Guinness sent a minute to Dr Rejman, (incorrectly dated as 1995) [DHSC0042937_032]. The minute stated,

> *"I had a meeting with the Permanent Secretary on Friday.*

> *He was 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.*
>
> *His view is 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.*
>
> *No specific action was requested, but it would probably be wise to undertake some contingency work on the sort of scheme favoured by John Marshall so that we can move quickly if necessary."*

2.42. On 9 January 1996 Ann Towner sent a minute to Mr Guinness and Karen Marsden [DHSC0042937_035]. The minute gave information to assist with a response to the Treasury and advised,

> *"The new PS(H) John Horam wishes to appear is sympathetic to the situation of haemophiliacs who contracted Hepatitis C and open to receiving and considering any information put forward. However no commitment to making any such payments has been made. Officials fully understand the financial and precedent implications of introducing even some form of limited "compensation scheme" and will continue to make these clear to Minister as opportunity arises, as they did when briefing for the debate in question.*
>
> *Treasury may find it reassuring to hear of the outcome when PS(H) recently wanted to amend a private office reply on the subject to insert "at present" in the phrase" we have no plans to make payments". Officials explained their concern that this might lead to expectation of a change in policy. PS(H) said that he understood this, and subsequently accepted a revised draft reply (copy attached) which emphasised the sympathy and readiness to study facts arguments but left the original wording about having no plans to make payments intact. Perm Sec was advised of*

> *officials concerns, and has since confirmed that he is content with the approach accepted by PS(H).*
>
> *Officials will of course continue to keep a watch on relevant correspondence etc. And of course PS(H) cannot alter the Department1s policy without the agreement of sos who - recent correspondence suggests - retains a firm line."*

2.43. On 12 January 1996, Marguerite Weatherseed, made a request to Mr Guinness, which was copied to my office [DHSC0003883_123] Mr Horam wanted to explore the issue of a payment scheme further including details of the costs of such a scheme. The request stated,

> *"As I mentioned in our telephone conversation earlier today, PS(H) has been giving further thought to the issue of awarding compensation to haemophiliacs who contracted hepatitis C before routine screening of blood products was introduced. He is well aware of our current position on this issue and the reasons for this. However, against a background of mounting political pressure, he would like to explore the options for offering compensation, if only to assure himself that we have done all that is feasible.*
>
> *I would be grateful if you could prepare a submission for PS(H) setting out costed options for compensation (which could vary, for example, according to factors such as age, the existence of dependents, hardship factors, limited to those who have actually developed Hep C). This should include an assessment of how far any of these options are likely to be acceptable to the Haemophilia Society.*
>
> *This should also provide advice on the likely availability of funds and the implications any change in policy might have in terms of triggering off demands from other areas, both from people (whether haemophiliacs or not) who were infected by blood, rather than blood products, and more generally (for example, if blood or blood products are shown in future to have transmitted some as yet unrecognised infectious agent)."*

2.44. On 18 January 1996 I responded to a letter sent to me by Sir John Major, enclosing one from his constituent regarding payment to haemophiliacs with HCV dated 30 November 1995 [HSOC0000144]. This is the letter referred to in the minute in paragraph 2.41 above. In my response I stated, [HSOC0000144],

> *"Most haemophilia patients were infected with hepatitis C before blood products were treated to destroy viruses. These patients received the best treatment available in the light of medical knowledge at the time.*
>
> *The Government does not accept that there has been negligence and we have no plans to make payments to such patients. On the more general issue of compensation, the Government has never accepted the case for a no fault scheme of compensation for medical accidents. It is unfair to others and still requires proof of causation which is often difficult to establish. Each individual case where a medical accident has occurred is a personal tragedy for both the individual concerned and their family and if the NHS is proved negligent in a Court it accepts its liability to pay damages.*
>
> *In the case of patients inadvertently infected with the HIV virus, the decision to make payments to those affected and to establish a hardship fund, was taken in the light of their very special. circumstances. Those affected were all expected to die very quickly-, and were subject to significant social problems, particularly ostracism. Hepatitis C is different from HIV. Many people infected with hepatitis C may live for a long period without any symptoms occurring, and only a very small proportion are expected to die from the disease.*
>
> *It is the Government's view that the most effective use of resources is to seek to improve the understanding, management and treatment of the condition. Only in this way can the impact of the disease on individual patients and their families be effectively minimised.*

> *The Department of Health is supporting an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with hepatitis C, and has made available £91,000 in 1995/96, with a commitment to further funding in 1996/97 and 1997/98 for this purpose.*
>
> *The Daily Telegraph report which Mr GRO-A mentions referred to research being carried out in America on gene therapy to produce cells which manufacture Factor VIII which is missing in patients with haemophilia. Factor VIII is made in the liver and the report suggests that this work. may help in treating patients with hepatitis C and other liver diseases.*
>
> *I can confirm that the Department of Health is currently considering several proposals for further research in relation to hepatitis C, to increase knowledge of its natural history and its optimal treatment. One example of this is that the Standing Group on Health Technology has identified the evaluation of the use of alpha interferon in the treatment of hepatitis C as a top priority in the NHS. Such developments are important to increase the evidence base upon which decisions can be made on the best treatment for each individual patient."*

2.45. As with the correspondence with Sir Edward Heath and Roy Hattersley, I did of course take a particular interest in correspondence with the Prime Minister and would have ensured that my correspondence with him accurately reflected the collective view taken by the Government – for which I was responsible.

2.46. On 29 January 1996 Paul Pudlo responded to Graham Barker's letter dated 19 December 1995 [WITN5290022], stating:

> *"You asked for details of the Department's proposals for research into Hepatitis C, The R&D Division are looking to, fund research into three areas of Hepatitis C virus infection, namely prevalence, transmission routes and the natural history of infection as follows: -*

Prevalence

The prevalence of HCV infection is not accurately known in the UK population; it is estimated to be between 0.1% and 1.0% of the general population. It would obviously be helpful to know this in order for the NHS to be able to plan most effectively for possible future health care needs, Recipients of previous blood donations from donors who have subsequently been shown to be hepatitis C positive after the introduction in 1991 of HCV antibody screening are being identified in the UK Departments of Health Look Back Exercise. Today it is thought most likely that the largest group of HCV infected people will be those who abuse drugs and share needles. Eowever1 it is important to obtain a comprehensive perspective, which is as accurate as possible.

Transmission

HCV can be transmitted· via the delivery of contaminated blood and blood products but this should no longer occur. Further research is required into other possible routes which are still possible and likely, for example between sexual partners and between an infected mother and her newborn child. The rates of transmission via different routes are also of much relevance and interest. A better understanding of transmission routes and rates would allow the introduction of improved public health education aimed at reducing the incidence of newly acquired infections,

Natural History

The natural history of HCV infection is presently not fully understood. rt may vary according to how the infection was acquired, viral load, host and viral genotypes, the presence of concomitant infection or illness, and subsequent life- style, Knowledge of the natural history of infection would be valuable when counselling infected individuals and determining their

> *most appropriate future medical management. It would also be extremely valuable knowledge for the planning of probable future public health care needs,*
>
> *Full research submissions addressing one or more of these three areas are being invited from experienced researchers. The awarding of research grants will be by a competitive tendering exercise. A total of £1 million has been made available for research into all these three areas." [HSOC0014304]*

2.47. On 31 January 1996 Mr Guinness sent a minute to DCMO and other Departmental Officials stating [DHSC0002533_147]; (attached draft) [WITN5290023],

> *"PS(H) has been giving further thought to the issue of awarding compensation to haemophiliacs who contracted hepatitis C before routine screening of blood products was introduced. He is well aware of our current position on this issue and the reasons for this. However, against a background of mounting political pressure, he would like to explore the options for offering compensation, if only to assure himself that we have done all that is feasible.*
>
> *I have therefore been asked to prepare a submission:-*
>
> *setting out costed options for compensation (which could vary, for example, according to factors such as age, the existence of dependents, hardship factors, limited to those who have actually developed HepC).*
>
> *assessing how far any of these options are likely to be acceptable to the Haemophilia Society*
>
> *providing advice on the likely availability of funds and the implications any change in policy might have in terms of triggering off demands from other areas.*

> *The submission is due with PS(H) on Friday 9 February. The Permanent Secretary has asked to see it a reasonable time before it goes up.*
>
> *I attach a draft, and would be grateful to receive any comments by close on Friday 2 February."*

2.48. Mr Guinness responded to Marguerite Weatherseed's request of 12 January 1996, the draft response appears to be undated and my office was listed in the intended copy list [DHSC0042937_014]. The draft response stated,

> *"This [the submission] focuses on a scheme confined to haemophiliacs but emphasises the pressures that are likely to emerge from other groups in comparable positions. None of the options presented nor the assumptions underlying them have been subjected to rigorous economic analysis and further work would be necessary before any of these could be taken forward. Similarly we should be in a better position to assess the acceptability of any scheme when we have received the Haemophilia Society's own proposals which are expected shortly."*

2.49. On 7 February 1996 I wrote to Roy Hattersley [HSOC0014327] following our meeting on 19 December. In my letter I stated,

> *"I thought it was a very useful meeting and I was particularly grateful for the opportunity to learn first hand about the experiences of people suffering from the effects of Hepatitis C.*
>
> *Firstly Mrs* GRO-A *wanted to know why her children* GRO-A *and* GRO-A *apparently had been refused alpha interferon treatment. We have made enquiries of the Birmingham's Children Hospital, where they are being cared for. I am very pleased to be able to say that the Trust have confirmed both* GRO-A *and* GRO-A *began treatment with alpha interferon from 17 January. I understand there had been a problem in obtaining clearance from the ethics committee but that this has now been obtained and that their parents were informed on 9 January.*

> *I also promised to write about the evident delay in informing Mr GRO-A that he had been diagnosed as positive Hepatitis C. Having investigated, I understand that the decision about when to inform Mr GRO-A was made purely on clinical grounds. There is no evidence whatsoever of an administrative error or oversight. This is a local decision involving patient confidentiality and in the circumstances Mr GRO-A may wish to seek a full explanation from the consultant in charge of his case.*
>
> …….
>
> *Finally, following the meeting Mr Ross asked about a recent press release regarding the combined use of Thymosin and Alpha Interferon for Hepatitis C, showing favourable results. My officials have looked into this. Although the results appeared encouraging, we gather that the number of patients studied was too small to provide conclusive evidence. I understand that a clinical trial using a form or thymosin in the treatment of chronic hepatitis C is about to start in the UK. I have no doubt that we still have much to learn about this virus to inform future decisions about treatment. To this end you may wish to know my Department's R&D Division are currently looking to fund research into three areas of Hepatitis C virus infection, namely prevalence, transmission routes and the natural history of infection. A total of £1 million has been made available for research into all these three areas."*

2.50. On 7 February 1996 Mr Guinness sent the submission to Sir Graham Hart, who had asked to see the submission before it was put up to John Horam [DHSC0003883_107]; [WITN5290023].

2.51. The Permanent Secretary replied the same day [DHSC0042937_013]. Although this minute is dated 6 February 1996, from the content it is apparent it was written after having sight of the submission on 7 February 1996. In his response the Permanent Secretary noted,

> *"He thought you might be clearer about the "discretionary scheme" in paras 16-18. Theoretically it could stand on its own as a total response*

> *rather than, as with HIV cases, as a supplement to a lump sum scheme. At a cost of £12m a year it might look very attractive to Ministers. But could it in practice be a stand-alone scheme and if so could it really be done for £12m a year - surely the awards would be on a more widespread and generous basis than in the HIV schemes?"*

2.52. On 9 February 1996 Mr Guinness provided the final version of the submission responding to Mr Horam's request on options for a payment scheme for haemophiliacs infected with HCV [WITN5290024]; [SCGV0000166_015]. On its face, it does not appear that the submission in its final version was copied to my private office. As requested by Mr Horam the submission set out details of the likely costs of a payment scheme. As noted in para 2.30 above I was aware that Mr Horam was making such enquiries and remember discussing them in the weekly informal meetings in which ministers met with senior officials, as well as in other informal settings. The record shows that the senior team at the Department (including Sir Graham Hart, the Permanent Secretary) were all aware of the continuing political (and Treasury) interest in the subject.

2.53. Under 'conclusions' the submission of 9 February 1996 set out the following,

- *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 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.*

2.54. On 20 February 1996 Mr Guinness sent a minute to Mr Billinge, (who led on the subject in the Departmental Press Office), copied to my office, reporting that the Haemophilia Society's report was being published that day. [DHSC0004469_007]. The minute gave 'lines to take' and stated that Mr Horam was due to meet representatives of the Society on 6 March 1996 to discuss the report.

2.55. On the same day Ann Towner sent Mr Guinness and other policy leads an initial draft briefing for the meeting due to take place on 6 March 1996 which contained lines to take and a copy of the Haemophilia Society's report. [WITN5290025].

2.56. On 22 February 1996 my private secretary sent a minute to Mr Guinness headed '*Compensation for Hepatitis C'* stating, [WITN5290026]

> *"I am writing to give you advance warning of a meeting on this subject.*
>
> *As you will be aware, John Marshall MP has been a relentless advocate for compensation for those haemophiliacs who have contracted hepatitis C as a consequence of NHS treatment. The Prime Minister has asked the Secretary of State to take the issue up with Mr Marshall, and therefore*

> *Mr Dorrell has decided to invite Mr Marshall in for a 1 hour meeting, at which he will have an opportunity to air his views. Anne Murie will contact Mr Marshall to offer him a meeting, and liaise with you direct to agree which officials should be present and a deadline for briefing."*

2.57. On 28 February 1996 John Horam's office sent a minute to Mr Guinness, copied to my office. The minute stated, [DHSC0003883_101].

> *"Thank you for your submission of 16 February*[1] *which discussed possible options for compensating those haemophiliacs who contracted hepatitis C before routine screening of blood products was introduced.*
>
> *As I explained during our telephone conversation yesterday, PS(H) wants to consider these options carefully. He is meeting the Haemophilia Society on 6 March and would like to hear their suggestions before he starts to form any firm views. He will almost certainly want a meeting with you after that to discuss how to take this forward.*
>
> *In the meantime, 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.*
>
> *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*

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[1] The minute erroneously appears to reference Mr Guinness' submission as 16 February. The correct date appears to be 9 February see para 2.52

> *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."*

2.58. This indicates Mr Horam wanted further detail on the option that had been suggested by Mr Marshall of restricting a payment scheme to those who had gone on to develop cirrhosis, which he plainly felt had not been sufficiently addressed in the submission setting out options.

2.59. On 29 February 1996 Sir Graham Hart's office sent a minute to John Horam's office, copied to my Private Secretary [DHSC0003883_100]. The minute stated,

> *"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.*
>
> *He therefore recommends extreme caution in dealing with Mr Marshall's proposal."*

2.60. On 5 March 1996 John Horam's Private Secretary responded saying that Mr Horam had noted Sir Graham Hart's points and that he would "*…certainly bear these in mind"* [DHSC0003883_099].

2.61. On 11 March 1996 Mr Guinness provided a further submission to John Horam, copied to my office [WITN5290027]. This submission was provided in response to Mr Horam's request for additional information on the financial implications of a scheme along the lines suggested by Mr Marshall. The submission concluded that best estimates, excluding administrative costs, for a scheme based on cirrhosis would be 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	*	*

2.62. On 26 March 1996 John Horam met with the Haemophilia Society. Whilst I did not attend this meeting, I can see from reviewing the papers, in particular the briefing from the Haemophilia Society, that discussion would have been had surrounding the request for payments [WITN5290028].

2.63. On 4 April 1996 Paul Pudlo sent a minute to John Horam's office [DHSC0042289_176]. This minute referred to a further meeting with Graham Barker of the Haemophilia Society the day before. The minute talked about further proposals for a scheme put forward by the Haemophilia Society and stated,

> *"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.*

> *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 estimates 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.*
>
> *The Society will be expecting a response to their proposals in due course. They recognise that this may take some time for Ministers to consider, given the sums involved. They have offered further talks if Ministers think this would be useful. However it is likely that eventually, they will deem failure to announce an intention to establish a scheme as an indication that one is not being contemplated."*

2.64. It is fair to say that between his appointment in November 1995 and April 1996, John Horam devoted considerable time and energy to reviewing options for dealing with these issues. He did so with my full backing as Secretary of State and was supported in his work by the responsible section heads within the Department. I believe the record shows that the civil service, including the Permanent Secretary, engaged with ministers in a serious review of the options available to the government, and that ministerial colleagues outside the Department, including the Prime Minister, were also aware of and interested in the process. It is also worth noting that this process was proceeding alongside the normal business of the Department of Health – including at that time, the process by which the specialist advisory committee advising the government on BSE was changing its advice on the transmissibility of spongiform encephalopathy to humans – which led to my statement to the House of Commons on that subject on 20 March 1996 [WITN5290029].

2.65. On 15 April 1996, I responded to a letter from Rt Hon David Hunt MP sent to me on behalf of his constituents [DHSC0003201_011]; [WITN5290030]. The response defended the Government's position on a payment scheme for haemophiliac HVC sufferers and contained the same paragraphs as in the correspondence referred to at para 2.44 above. It is apparent that this was the current Departmental line at the time, that the Government had no plans to set up a payment scheme and did not accept negligence. The letter went on to explain that payment was made to HIV sufferers due to their special circumstances and that the Department was supporting an initiative by the Haemophilia Society by making available £91,000 in 1995/96 with a commitment to further funding through 1996/97 and 1997/98.

2.66. The letter also mentioned the Macfarlane Trust payment scheme as the constituents in this case were also HIV sufferers.

2.67. On 19 April 1996 Ann Towner sent to my diary secretary, Miss Murie, a revised briefing pack. This was because the meeting which was initially due to take place on 27 March had been deferred to 29 April, probably due to the issues raised at the same time by my announcement about BSE on 20 March (although the meeting note indicates it took place on 24 April) [WITN5290031]. Under the heading '*Compensation – Line to take*" the briefing stated,

> "*Great sympathy for those infected with hepatitis C as a result of NHS treatment, but these patients received the best treatment available in the light of medical knowledge at the time. No fault or negligence on the part of the NHS has been proved, and we have no plans to make special payments. The Government remains opposed to no-fault schemes.*
>
> *Our view remains that the best way the government can help is to encourage research, and best treatment for those infected, as well as supporting voluntary groups working with those infected. I really do think it is better to spend NHS money on treating patients than on paying*

> *compensation to people who had the best possible treatment available at the time. [See DH action para 2.8}*
>
> <u>*If pressed for a scheme based on paying people with cirrhosis*</u>
>
> *Our objections to a no-fault scheme are not simply financial. Furthermore, there are problems about any scheme based on making payments to people who have developed cirrhosis. Because it is already over I0 years since any haemophiliacs were infected, there would be- quite a substantial amount payable now, though the subsequent costs would be spread over a number of years. We also do not think we could confine compensation to haemophiliacs - it would have to be extended to people infected through blood transfusion, as we did with HIV infection. Again there would be quite a substantial amount payable now, with subsequent costs spread. There are al.so problems about diagnosing cirrhosis. Finally, it is clear that the Haemophilia Society would not be satisfied with such a scheme."*

2.68. On 23 April 1996 Paul Pudlo sent a minute to Mr Dobson referring to his email to Ann Towner of the same day [WITN5290032]. In his minute he stated, [DHSC0004756_041]:

> *"The reference in the briefing which you mention relates to evidence given by the SofS to the Health Committee (Public Expenditure Enquiry) on 19 July 1995. Asked by John Marshall about compensating those who suffer premature death through contaminated blood, SofS referred to his previous experience with the subject as a health minister and replied :-*
>
> *"I believe it remains true now as I asserted then that there is a choice to be made about whether the Health Service uses its resources to compensate those who have suffered but through no fault of the Health Service where there has been a breakdown but without fault, whether that is a higher priority than the treatment of today's and tomorrow's*

patients. I said then and I still believe it very strongly to be true that any patient who undertakes a course of medicine must accept that there is a risk attached to modern medicine and in cases where a patient is damaged but without any fault, I do not believe that it is sensible use of NHS resources to provide compensation in those cases. Of course that is in no sense to undermine the quite proper obligation that rests when things go wrong through somebody's negligence. Where there is no fault, I am not in favour of compensation as a principle.“

Later in the hearing John Marshall returned to the subject asking :-

"Would you not agree that there is something illogical when those who have suffered early death through HN are compensated but sometimes within the same family another haemophiliac suffered an early death through cirrhosis of the liver, through hepatitis C, and has received no compensation at all. Do you not think that it is worthy of re-examination, particularly as there are so few people involved?".

SofS replied :-

“I cannot deny that there is an illogicality there because the haemophiliac who contracted AIDS as a result of blood transfusion (sic) was provided with compensation in contravention of the principle I enunciated to the Committee. We can only give the grantee that there will be no illogicality if we extend the same form of compensation more generally than we have yet done and I am not in favour of doing that for the reason I gave to the Committee.".

I am not sure that SofS's statement signals a new anxiety about the HIV precedent. He has consistently opposed any form of no-fault compensation but seems to be saying that it is preferable to live with what he regards as an anomaly than to remove it by making it the norm. Such a candid position may be difficult to defend publicly since it could be taken *as a suggestion that the HIV infected patients are not deserving of the compensation they receive.*

However this public evidence, so far, has not been used by proponents of compensation. There is a tacit recognition among both sides of the argument that, with the benefit of hindsight, the distinction made between the plight of HIV and HCV infected haemophiliacs is looking increasingly tenuous. It is now known that HIV is not as rapidly fatal as was thought at the time of the settlement but HCV is worse than predicted. This erosion of the clinical difference between the groups has weakened the proposition that HIV was a special case. This has been exploited by eg the Haemophilia Society who argue that there is now no moral basis for treating the two groups differently. They accept that there is no question of negligence in either case. Encouraged by Ministers responses to John Marshall they view the affordability of a settlement as the current pivotal issue.

Whilst your proposed alternative strategy is attractive for the reasons that you suggest, I am not sure either that it would be consistent with the HIV legal view at the time or how we could argue that the legal position vis a vis HCV was so much better both for haemophiliacs and blood transfusion cases. In any event I doubt that campaigners for compensation would be any more persuaded by a legal distinction than they are a clinical one. Additionally Ministers might be seen to be backtracking on a public position which has consistently held that the Department was not at all vulnerable on the issue of negligence and we might risk forcing those who have so far desisted to go down the litigation route turning the current dribble of writs into a flood.

Clearly this has implications that go wider than the blood-based infections but so far as HCV goes I am not, on balance, in favour of the legal argument. If others feel otherwise I would suggest that we need to

> *carefully consider what was said publicly at the time of HIV settlement before proceeding to a submission."*

2.69. It is worth commenting at this point that I believe that Paul Pudlo's minute of 23 April 1996 goes to the heart of the matter. My evidence to the Select Committee of 19 July 1995 (two weeks after I took office) sets out my view clearly – and it remained the Government's view throughout my period of office. I did not (and do not) support the principle of no-fault compensation payments to NHS patients who suffer as a result of the inevitable risks associated with medical treatment. I agree strongly with Sir Graham Hart's comment (quoted at paragraph 2.59) "*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".*

2.70. On 24 April 1996 I met John Marshall with Mr Pudlo. I have reviewed the meeting note and briefing that was provided prior to the meeting [DHSC0041255_074].

> *"Mr Marshall set out various reasons why the Government should consider paying "no fault" compensation to haemophiliacs who had contracted Hepatitis C as a result of NHS treatment: the precedent of HIV compensation; international comparisons; humanitarian reasons, political advantages etc. 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. He also suggested that a compensation scheme which paid a lump sum to those sufferers who went on to develop cirrhosis might cost the Government £18m in year one, and £18m over the next ten years. He did not consider this to be an excessive sum. Mr Pudlo pointed out the difficulties of compensating this group without also compensating non-haemophiliac recipients of blood donations who had contracted Hepatitis C as a result of NHS treatment. This would raise the costs to perhaps £40m in year one, and £40m over the next ten years. Mr Marshall agreed*

> *that it would be difficult to distinguish between the two categories of patient.*
>
> *The Secretary of State 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 life if £40m were available and it were invested on their behalf instead. In the circumstances it would be difficult to justify £40m no-fault compensation for haemophiliacs. It was agreed that Mr Marshall's best course of action may be to seek funds which had not been allocated for health purposes. Mr Marshall said that he would consider writing to the Prime Minister for access to Government contingency funds. Mr Marshall decided not to pursue the question of an independent inquiry or tribunal.*
>
> *Mr Marshall also remarked on the compensation schemes which had been set up by US pharmaceutical companies, and questioned whether these companies could be encouraged to make similar arrangements for Hepatitis C sufferers in the UK. Without knowing the detail of the scheme operated in the US, Mr Dorrell commented that he could foresee difficulties in persuading private sector companies to pay no-fault compensation, but nonetheless he would ask officials to investigate the situation."*

2.71. From the note I can see that Mr Marshall was advised to seek funds which had not been allocated for health purposes and that he had said he would lobby the Prime Minister for access to contingency funds. Mr Marshall also raised compensation schemes set up by US Pharmaceutical companies and suggested that these may provide a precedent for financing compensation to UK haemophiliacs. I agreed to ask officials to investigate the situation.

2.72. On 1 May 1996 Mr Pudlo sent to my office a minute following up on Mr Marshall's suggestion [DHSC0003883_089]. The minute stated,

> *"I have looked into John Marshall's suggestion that US pharmaceutical companies in the had been involved in financial settlements which could provide a precedent for financing compensation to UK haemophiliacs. As mentioned at the meeting, the US based healthcare company Baxters are currently engaged in negotiating a settlement with patients infected with Hepatitis C through use of their immunoglobulins. Beyond this Japanese pharmaceutical companies are known to be involved in a Government settlement to patients infected with HIV through blood products. We can find no evidence of any compensation schemes funded by the private sector that have any bearing on the situation faced by UK haemophiliacs.*
>
> *I don't recall any commitment to communicate further with John Marshall on this subject and I can see no advantage in doing so; but if SofS was so minded, all we could do is invite Mr Marshall to provide us with details."*

2.73. On 10 May 1996 Mr Pudlo sent a further minute to my office stating, [DHSC0042289_107].

> *"Further to my note of I May 1996, I have now received information from the British Embassy in Washington which throws light on John Marshall's point about US pharmaceutical companies funding a settlement to Haemophiliacs. This is drawn from an article published in the Wall Street Journal on 22 April 1996 (copy available).*
>
> *According to the article a number of companies (including Bayer) have proposed a joint settlement of $640m in an attempt to conclude the long-running litigation by US haemophiliacs infected with HIV through the use of blood products before heat treatment was introduced in the mid 80s. There are some 600 lawsuits current but we believe the number of haemophiliacs infected to be very much greater (there were over 1,000 in the UK). The settlement, which includes $40m for legal costs is*

> *conditional upon 95% of all plaintiffs accepting, by 20 May. Commentators forecast that it will be rejected by most as insufficient.*
>
> *In answer to John Marshall's proposal it can be said that this offer is solely about HIV and makes no reference to Hepatitis C. The UK settled the HIV cases some years ago. The involvement of commercial companies reflects the difference between the health care systems in the two countries and the way that blood products were supplied. It provides no basis for an approach to commercial companies in the context of the current claims for Hepatitis C compensation even if this were though appropriate.*
>
> *I do not think this alters my earlier advice or the line proposed in the PM's letter to John Marshall, but I will provide a draft if SofS is now minded to write to Mr Marshall."*

2.74. On 16 May 1996 the Prime Minister responded to a letter from Mr Marshall [DHSC0006947_156]; [WITN5290033] The letter was forwarded to my office on 1 May 1996 for a draft response. The response stated, [DHSC0006947_157].

> *"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.*

> *I am unable to comment on the possibility of any commercial company accepting liability through funding a settlement and I do not think it would be appropriate for us to explore that.*
>
> *You ask whether the National Lottery Charities Board (NLCB) may be able to fund a settlement. The NLCB makes its decisions on applications for lottery funds independently of the Government. I cannot direct the Board to fund a particular project. However, you may be interested to know that the Board is encouraging applications from charities working in the fields of health, disability and care in its current funding round. It is, therefore, possible that haemophiliacs and those suffering from Hepatitis C might be able co benefit from lottery grants, but this would be a matter for the Board to decide in response to any applications received."*

2.75. On 29 May 1996 Mr Pudlo minuted John Horam's office, copied to my office [WITN5294010]. He provided a draft letter in response to the Haemophilia Society's compensation proposals. He stated,

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

2.76. On 12 June 1996 Mr Pudlo sent John Horam's office a briefing ahead of a meeting due to take place on 25 June 1996 between John Horam and John Marshall [DHSC0041255_073]. I was not copied into this briefing.

2.77. On 17 June 1996 Paul Pudlo wrote a minute to John Horam's office following up on his briefing [DHSC0042289_032]. I was not copied into this minute. The letter stated,

> *"We have learned that the Rev Tanner (Chairman of the Haemophilia Society) will be writing to PS(H) on 19 June pressing for resolution of the issue of compensation. We understand that he will also propose*

> *that as an interim measure a nominal amount should be provided for all Hep C infected haemophiliacs. The Society will see this as a step forward that will allow them to satisfy members that they have established the principle of compensation without conceding on the amount and allow Ministers the opportunity to make an affordable gesture towards settlement. To concede this would compel equal treatment for non-haemophiliacs and would make it difficult to resist a more substantial settlement at a later date.*
>
> *The Haemophilia Society will be holding a meeting of interested MPs including John Marshall, Sir Geoffrey Johnson-Smith and Alf Morris on 19 June. We understand that the meeting has been called to discuss strategy for the campaign for compensation before the Summer recess. It is likely that the Society will seek to brief John Marshall for his meeting with PS(H) next week".*

2.78. A minute of the meeting records that the two key demands Mr Marshall put forward on behalf of the Haemophilia Society were [DHSC0041255_072].

> *"i)To award an additional £20m to the Macfarlane Trust to make provision for haemophiliacs facing hardship;*
>
> *ii)To award £1Ok to each haemophiliac infected with HepC (total cost £30m)"*

2.79. The minute further recorded that John Horam, "*stressed that it would be difficult to justify payments of this magnitude with so many competing demands on the health service…".* Mr Marshall acknowledged this point and went onto suggest alternative sources of finance such as Government's contingency reserves, grant from the National Lottery or an out of court settlement from the pharmaceutical industry.

2.80. On 9 July 1996 John Horam's office sent a minute to Paul Pudlo referencing a meeting which took place the day before. This minute was copied to my office

[DHSC0041255_070]. The minute made a request from Mr Pudlo to draft a letter to the Haemophilia Society 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.*
>
> *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."*

2.81. On the same day, Information Division, responded saying the letter to Haemophilia Society may be best deferred until after the 19 July 1996 as the judgment in the negligence action against the Department on CJD and human growth hormone was expected on this day [WITN5294012]. They further suggested that if the Department lost "*there may possibly be implications for other groups*".

2.82. On 17 July 1996 Mr Pudlo sent a minute to John Horam's office copied to my office stating, [DHSC0006348_062]:

> *"I attach a draft letter in response to the Haemophilia Society for PS(H)'s consideration. Given the expectation of the CJD judgement on 19 July, it would be as well to hold of sending until we have seen the terms of that decision. The judgement is only likely to affect the terms of the reply if it*

> *finds against the Department in a way that has clear implications for Hepatitis C compensation."*

2.83. On 19 July 1996 the High Court ruled that the Department of Health had been negligent in the case of eight families whose children had died of CJD as a result of treatment received before 1 July 1977 [WITN5290034]. Although these cases were not directly relevant to the cases of patients who received transfusions of infected blood, the publicity surrounding the CJD case was part of the context in which infected blood cases were being considered.

2.84. On 22 July 1996 I wrote to the Rt Hon Tim Renton MP in response to a letter from one of his constituents [DHSC0041170_098]. The response included the Departmental line as follows,

> *"I was very sorry to read that GRO-A: has contracted the hepatitis C virus. The Government has great sympathy with those patients who may have become infected with hepatitis C through blood transfusions or blood products. However, medical procedures rarely come without risk, and these are not always fully known or capable of being guarded against at the time. Most blood transfusion patients were infected with hepatitis C before September 1991, when blood was treated to destroy viruses. You may wish to note that the heat treatment to which your constituents specifically referred related to blood products alone, as blood cannot be heat treated.*
>
> *Those patients accordingly received the best treatment available in the light of medical knowledge at the time. The Government does not therefore accept that there has been negligence and we have no plans at present to make payments to such patients. I can, however, assure your constituents that we do not see the issue of compensation for patients as one restricted to haemophilia patients alone.*

> *We also agree with your constituents that the most effective use of resources in this area is to seek to improve the understanding, management and treatment of hepatitis C, and this we are doing. Only in this way can the impact of the disease on individual patients and their families be effectively minimised.*
>
> *The Department has provided an additional £1 million for a number of research studies to improve our knowledge of hepatitis C in respect of incidence and prevalence, origins, and the natural cause of any disease that may develop as a result of hepatitis C. You may also be interested to note that the Medical Research Council is commissioning a study into the use of Interferon A for the treatment of hepatitis C." [WITN5290035]*

2.85. On 29 July 1996 Mr Guinness sent a minute to John Horam's office [DHSC0006348_055]. This minute was copied to my office. Clearly John Horam had sought advice on whether the human growth hormone/CJD judgment impacted on the intended correspondence to the Haemophilia Society. The advice from Mr Guinness was,

> *"I do wonder about the wisdom of writing to the Haemophilia Society until media interest in the CJD case has died down. Although the fact that we have been found negligent in one case does not mean that we should suddenly change our policy and decide to pay compensation where no negligence has been demonstrated (nor, indeed, alleged by the Haemophilia Society itself, as distinct from a number of potential individual litigants who are currently seeking Counsel's opinion), a clear statement to the Haemophilia Society at this stage that we are not prepared to pay financial compensation might be presented as the Government having forced one set of unfortunate people to endure the uncertainties of legal action now doing the same again. Indeed, the fact that the letter simply restates a long-held position might lead observers to conclude that the letter was almost a defiant throwing down of the gauntlet in the face of defeat over CJD."*

2.86. The advice went further to suggest that if Mr Horam felt he must write early next week, then a line should be included referring to the CJD case.

2.87. On 3 September 1996 my Private Secretary wrote to Mr Hattersley in response to his letter dated 12 July 1996. This was a holding reply acknowledging receipt of his letter enclosing a further letter from Mr GRO-A Chairman of the Manor House Group. The letter stated I would provide a full response upon my return to the office later in September [WITN5290036].

2.88. On 11 September 1996 Christine Corrigan, a policy official, responded to John Horam's request for a round-up on blood issues copied to my office [DHSC0041255_064]. The minute stated,

> *"...there have been no new developments which would indicate that reconsideration of the Department's position on the claim for no-fault compensation might be warranted. Nor does there appear to be any further scope at present. (other than the assurance already given in the draft letter of PS(H) 's positive consideration of future applications for Section 64 grants) for offering any additional support outside of such a scheme."*

2.89. The minute went on to advise on the issue of an amendment in light of the CJD Judgment that it was "*...strongly recommended...should not add anything further on that issue...".* The minute went onto provide suggested wording should Mr Horam still wish to include something in his letter.

2.90. Mr Horam's response was delayed by a week as I wished to dovetail his letter with my reply to Roy Hattersley MP on the same subject. My private secretary communicated this to Christine Corrigan on 17 September 1996 [WITN5294014].

2.91. On 18 September 1996 John Horam's private secretary notified Ann Towner of the change in timetable [WITN5294015].

2.92. On 1 October 1996 I wrote to Roy Hattersley as follows, [DHSC0041255_063]

> *"After much thought, we have concluded that it would not be appropriate to offer financial compensation to haemophiliacs who have been infected with Hepatitis C. I will explain our reasons for this, but I should first stress that we shall continue to listen to the arguments and look at other ways in which we can provide help.*
>
> *We have already made very clear our deep sympathy for all those affected by this inadvertent tragedy. I have been very touched by the real problems that they clearly face and we are committed to doing what 1 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. 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, whlch would be both unworkable and unfair. This is a point that was considered in relation to the settlement for 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 we have considered a wide range of options) involve the expenditure of substantial sums of public money. We have a duty to consider the effect of such a sizeable sum on other heath service expenditure. That duty has led us to conclude that funds that are available to the NHS, from whatever source, are best used in direct patient care.

Mr GRO-A's letter, like that from the Haemophilia Society, identifies a need for progress in a number of areas, such as the treatment and care of those infected, research and public education. We entirely share their aim to achieve progress in these areas. A key priority must be to improve our understanding of the disease. 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 of 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. Local purchasers can then make informed decisions 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 we believe that public education, important as it is, can only proceed at a pace determined by our developing understanding. Information that is no 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.*
>
> *We have supported an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with the 'Hepatitis. C Virus, with a grant of over £90,000 in the last financial year and £117,000, in 1995-97 {on top of core funding of £35,000 last year and £38,000 in 1990-97) We have told the Society· that we would welcome any proposals from them to provide continuing support to this group as part of the Society's ongoing core activities, when they bid for further Section 64 grant funding. This is an area where resources can be directly targeted to provide practical help and improve services to infected haemophiliacs."*

2.93. John Horam's letter to The Rev Prebendary A J Tanner, the Chairman of the Haemophilia Society, was also sent on 1 October 1996 [HSOC0023572]. In his letter Mr Horam set out the reasons why financial compensation to haemophiliacs infected with HCV would not be appropriate. He cited two reasons in particular,

> *"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 for 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 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.*
>
> *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."*

2.94. On 3 October 1996 the Rev Prebendary A J Tanner responded to this letter. The response was copied to my office with a handwritten note asking Mr Guinness to advise and "*draft a reply as appropriate*" [HSOC0014299]. In his response Mr Tanner expressed deep disappointment with the Government's response and stated that the Haemophilia Society had never suggested there had been negligence on the part of the NHS but that an ex-gratia payment is the minimum required to alleviate immediate needs. He also stated that they were not seeking compensation but asking for a "*…compassionate approach to the strong moral arguments involved"* and further stated, *"We do not accept that such an approach would set a precedent for no-fault compensation".*

2.95. On 7 October 1996 John Horam appeared on a World in Action broadcast. Having reviewed the transcript, I can see that when asked about payment to HCV sufferers he responded [HSOC0008602],

> *"At the end of the day I have to say it is better to spend money on health care, direct patient*
>
> *care for haemophiliacs, for haemophiliacs with hepatitis C, or indeed anybody else who is ill rather than compensation."*
>
> ....
>
> *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".*

2.96. While Mr Horam continued to lead on the subject matter of payment/compensation to HCV sufferers, he did so with my full support and was speaking on behalf of the Government. The record shows that there had been repeated ministerial and official engagement on the issue at the highest level, but the Government had concluded that, while it recognized the distress of the victims and their families it did not support a change in its position on the principle of compensation payments where no fault was involved.

2.97. On 25 October 1995 Mr Horam responded to the Haemophilia Society's letter of 3 October 1996 [HSOC0003918]. In his response John Horam stated that the reasons for not providing financial help "*hold good*" however you choose to describe it (i.e. whether it was labelled as compensation or as an ex gratia payment). The response also mentioned the central funding of recombinant products for patients with haemophilia.

2.98. On 21 November 1996 Sir John Stanley wrote to me [DHSC0046935_239], copying a letter from his constituent [DHSC0046935_240]. I responded to this letter on 2 December 1996 as follows, [DHSC0046935_238].

> *"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 for HIV cases. The provision agreed then included the establishment of the Macfarlane Trust which gives help to those who contracted HIV through treatment for haemophilia, and their families. We continue to review the Trust's funding, as necessary. When we agreed to make payments to those infected with HIV, it was convinced by the very special nature of the disease and by arguments that it would not lead to further similar claims for compensation.*
>
> *Mr GRO-A mentions that the blood products derived from blood given by paid donors in the United States seem more likely to have been infected with hepatitis C then products derived from unpaid voluntary British donors. However, the frequency of infection even in the UK donor population suggests that in cases where haemophilia required multiple treatment with cryoprecipitate, or more recently, since the early 1970s, Factor VIII concentrate, then the patients would all have become infected whether the blood came from the United States or was from UK voluntary donors, until viral inactivation of blood products was introduced in 1985. Unfortunately, therefore, virtually all haemophiliacs treated prior to 1985 with cryoprecipitate or Factor VIII concentrates are infected with hepatitis C.*
>
> *With regard to the treatment of haemophilia, and in particular the use of recombinant Factor VIII products, the Department's aim is to ensure*

> *that the best healthcare is obtained for the resources available. We believe 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 VIH than that of any other patient where alternative treatments are available. Healthcare providers will need be assured that demonstrable benefits will be achieved if extra costs are to be spent on one group of patients with correspondingly less available for others. In making that decision in the case in question, providers will no doubt take into account the fact that since the introduction of the viral inactivation processes in 1985 plasma derived Factor VIII had had a good safety record; furthermore, all currently licensed forms of recombinant Factor VIII use plasma derived albumin as a stabiliser, they are not, therefore, wholly artificial and free from risk. I also understand that recombinant products themselves are not without side-effects.*
>
> *Questions of value added tax are for Customs and Excise, who ruled last year that recombinant Factor VIII products, like other recombinant pharmaceutical products, do not qualify for statutory relief from value added tax because they are neither human blood nor derived from human blood. This is on the basis that the human albumin used is present as a stabiliser, not as the active ingredient. However, we understand that a tribunal is to consider that ruling shortly."*

2.99. On 11 December 1996, a private members debate on haemophiliacs infected with HCV took place, secured by John Marshall. John Horam replied for the Government. Mr Horam repeated the Government's deepest sympathy for those infected and the reasoning behind the Government's decision not to establish a payment scheme [DHSC0041255_130].

2.100. On the same day the Rev'd Tanner from the Haemophilia Society wrote to the Prime Minister [HSOC0000161]. The letter was headed, *"Petition calling for Government support for people with haemophilia infected with hepatitis C*". The letter further stated,

> *"There is a great depth of feeling among the haemophilia community that they are being dealt with unjustly by the Government and are simply being forgotten and some left to die."*
>
> ……
>
> *You showed compassion and understanding when you made a settlement to help people with haemophilia infected with HIV. That settlement was made because it was morally right for the Government to provide help. The same moral argument applies to people with haemophilia infected with hepatitis C virus. Like HIV it is a blood borne virus, like HIV it devastates lives and can kill, like HIV it was contracted by people with haemophilia through their NHS treatment before 1986.*
>
> *Medical opinion states that it can take 20 - 30 years for HCV to cause severe liver damage. However, many people with haemophilia have been infected for over 20 years, often repeatedly with many different genotypes of the hepatitis C virus. This has put them at even greater risk of developing liver damage, and more than 60 are thought to have died already as a result.*
>
> *We accept that there are some differences between HIV and HCV. Nevertheless, the similarities between the two infections are strong and people with haemophilia infected with hepatitis C are suffering hardship and illness now, many have lost their jobs because of their HCV infection and are trying to make ends meet on benefits. We need action now. That is why we are handing in this petition today, and why we are holding a lobby of Parliament this afternoon."*

2.101. The letter stressed its request that the Prime Minster should intervene on the issue – although the record shows that he had in fact, by then, been involved for many months.

2.102. On 12 December 1996 I received a letter from Andrew Smith MP enclosing a briefing by the Haemophilia Society, that he received from a constituent of his, asking me what evaluation had been made of the Government position, "*in particular the basis for the Health Minister's assertion referred to*" [DHSC0046935_132]. I also received a similar letter from Michael Morris MP on the same day. [DHSC0046935_152].

2.103. On 18 December 1996 I responded in the following terms, to a letter from Paddy Ashdown MP [WITN5290037] enclosing one from a constituent, [DHSC0042313_082].

> *"We have deep sympathy for all those affected by this inadvertent tragedy. We have been very touched by the real problems that they clearly face and we are committed to doing what we 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.*

> *Second, all the proposals for compensation, and we 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 heath service expenditure. That duty bas led me to conclude that funds that are available to the NHS, from whatever source, are best used in direct patient care."*

2.104. On 19 December 1996 John Horam responded to Rev'd Tanner's letter of 11 December 1996, on behalf of the Prime Minster [HSOC0000161] (although there is a similar letter of response dated 3 January 1997) [HSOC0000347_007], setting out the Government's position as follows,

> *"The decision a few years ago to make payments to those infected with HIV through blood products was, as I have said, taken in the 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 the 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 appalling examples of ostracism. Of course, we now know rather more about the effects of HIV, and there is a much greater public understanding of how relatively limited are the ways in which it can be passed on*
>
> *If we were to provide payments on the basis of non-negligent harm in the case of those infected with hepatitis C, this would very quickly develop into a general no- fault compensation scheme, which would be both unworkable and unfair. I have also explained that all proposals for payments schemes involve the expenditure of substantial sums of public money. 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."*

2.105. On 23 December 1996 Claire Phillips, an official in the Specialist Clinical Services Branch of the Healthcare Directorate, Public Health Division, circulated a submission entitled, “Hepatitis C (HCV): the Current Position”, copied to my office [DHSC0004203_013]. This document set out a framework on handling the disease and options going forward.

2.106. On 3 January 1997 John Horam responded on my behalf to the letter from Andrew Smith MP setting out the Government’s position on the matter in the same terms as previous correspondence [DHSC0046935_131]; [DHSC0046935_132].

2.107. On the same day I responded to the letter from Michael Morris MP and also set out the Governments position on a payment scheme for HCV sufferers including the assistance being provided by the Government in other ways such as supporting an initiative by the Haemophilia study in undertaking a study into the best way to support its members and providing a grant of over £90,000 in the last financial year and £117,000 in 1996/97 (on top of core funding of £35,000 last year and £38,000 in 1996/97). [WITN5290038]; [DHSC0046935_151].

2.108. On 8 January 1997 Claire Phillips sent an email to other DH officials regarding her submission of 23 December 1996 stating, [DHSC0006855_008],

> *"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 Jess 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"*

2.109. On 22 January 1997 Christine Corrigan wrote to Graham Barker at the Haemophilia Society stating, [WITN5290039]

> *"We have now considered the request for grant aid in your application to us dated 27 September 1996. I am writing on behalf of the Secretary of State to offer the Haemophilia Society a grant up to a maximum of £60,000 for 1997/98.*
>
> *The grant is for the Society's "ABC" Hepatitis Support project."*

2.110. On 23 January 1997 John Horam sent me a note attaching the Hepatitis C submission from Claire Phillips [WITN5290040], stating:

> *"...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." [WITN5290041]*

2.111. On 4 February 1997 Claire Phillips wrote to the British Liver Trust stating, [DHSC0025908]:

> *"We have now considered the request for grant aid in your application to us dated 1 October 1996. I am writing on behalf of the Secretary of State to offer the British Liver Trust a grant up to a maximum of £38,250 for*

> *1997/1998, and, subject to the availability of funds approved by Parliament, for each of the two following financial years.*
>
> *The grant is for a national project to help people with hepatitis C by providing them with information about the disease, as well as advice and support."*

2.112. On 12 February 1997 I met with Mr Horam and Claire Phillips. A note of the meeting records [DHSC0004203_004]:

> *"Secretary of State's intention was that the framework for policy on Hepatitis C (HCV) should be to develop appropriate research and planned health promotion without causing unnecessary health scares or swamping NHS services.*
>
> *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.*
>
> *It was agreed that it would be very useful to have on record a statement of the Government's action on researching, preventing, diagnosing and treating HCV. If CMO was in agreement, a further CMO letter, this time to District Directors of Public Health, setting out all the elements of the policy should be sent out in the near future."*

My response to the Inquiry regarding the reasoning and rationale for resisting calls for a payment scheme for HCV sufferers

2.113. Having set out a chronology for the Inquiry, which I hope goes some way to assist in understanding what discussions took place during my time as SoS on the issue of a payment scheme for HCV sufferers, I will now address the Inquiries questions.

2.114. Firstly, I would like to say that although the entire content of correspondence referred to is not set out in this statement, letters sent to recipients informing of the Government's position always expressed the deepest sympathy the Government had for haemophiliac HCV sufferers. In addition the Government always stressed its desire to continue to listen to arguments and look to alternative ways it could provide assistance.

2.115. The Inquiry has asked me for the reasons and rationale behind resisting the calls for a payment scheme for HCV sufferers. I believe the chronology set out above and the content of the documents provides a comprehensive indication of the Government's reasoning behind refusing the calls. However I will summarise it here.

2.116. The Department's established view, which was formed on its understanding and knowledge of the issue at the time, was that:

i. HCV sufferers had received the best treatment available in light of medical knowledge at the time;

ii. There had been no negligence on behalf of the Government or care providers and therefore as the Government had never implemented a no-fault scheme for medical accidents it would be unfair to others who would still be required to prove causation which is often difficult to establish;

iii. The Government was willing however to assist in alternative ways such as seeking to improve medical understanding, management and treatment of the condition with a view to minimising the impact of the disease on patients and their families;

iv. The priority for public expenditure on NHS services should be the development and improvement of health services, rather than compensation payments for individuals who had received care which, although unsuccessful, was based the based available knowledge at the time, and did not involve fault on the part of the care providers.

2.117. Where parallels were drawn between haemophiliac HIV sufferers and haemophiliac HCV sufferers the Government's view was that:

i. A payment was made to HIV sufferers in light of their very special circumstances;

ii. Those affected with HIV had their life expectancy shortened drastically;

iii. They were subject to significant social problems, particularly ostracism;

iv. HCV was different in that many people with HCV may live a long life without any symptoms occurring;

v. Only a small proportion were expected to die from the disease.

2.118. The Department communicated with the Haemophilia Society on a regular basis to explore the option of a payment scheme. I would also add despite the Government's position remaining unchanged, the Government maintained an open dialogue with the Haemophilia Society and always reminded them that we were ready to listen to any further points or explore other ways in which we could assist.

2.119. The Government was providing assistance through other initiatives as set out in the briefing for the meeting with John Marshall in April 1996,

> *"Steps already taken by the Department to improve understanding and treatment of the disease include:*
>
> *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 vims, with a grant. of over £90,000 this*

financial year and £117,000 in 1996-97 (on top of core funding of £35,000 this year and £38,000 in 1996-97).

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 transfusion. 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 on establishing 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 were identified by the Society, au of which have been resolved."* [DHSC0041255_074]

2.120. In addition, the Government also provided further s.64 funding, on top of the Society's Core Grant. The Haemophilia Society was provided with a project grant of £60,000 in 1997/98 financial year, see paragraph 2.1092.107.

2.121. It is true that the Department of Health had a strong departmental view that no-fault compensation is a "slippery slope", but it is also true that this view corresponds with my own settled view (then and now, and articulated to the Select Committee on 19 July 1995) that it is undesirable to make payments of no-fault compensation for unsuccessful treatments provided in the past which can only have the effect of prioritising such payments over the commitment of resources to improving care for current and future patients. It is obviously true that patients who are the victim of sub-standard or negligent care should be compensated, but I believe it is equally obvious that progress in health systems will be significantly impeded if every advance creates the expectation of compensation for earlier generations of patients who did not receive the benefit of such advances. As I have noted in this statement this position gives rise to uncomfortable conversations, but I strongly believe it is the right position to adopt.

2.122. It is of course open to governments, as a separate issue, to provide support to groups of citizens who face particular difficulties, and all ministers should be open to such considerations. It is however, in my view, important that consideration of these humanitarian factors is not confused with payments to people who receive care to a standard which is later enhanced by developing scientific understanding.

2.123. As I have noted earlier, the record shows that John Horam led ministerial engagement on the subject, but he did so on behalf of the whole government and with the active engagement of officials (including the Permanent Secretary) and other ministers, including the Prime Minister and me. It was an exercise of collective responsibility in action. He investigated the likely costs involved and concluded on the figures and with the advice of Departmental officials that the

Government's position should not change as the funds would have to come from the DH budget which would otherwise be used for patient care.

Departmental Lines

2.124. The Inquiry has directed my attention to statements such as "*the best treatment available in light of medical knowledge at the time*" used in correspondence sent to MPs' constituents, and asked:

- whether this language reflected Departmental lines;
- if so whether I probed or questioned these lines;
- whether I had cause to question this line in the light of challenges to that narrative from constituents, campaigners or other Members of Parliament.

2.125. The record shows that this was not a major element of the discussion between officials and ministers; I believe this was true for several reasons:

a) Most importantly, at least to my recollection, I do not believe the proposition was substantially challenged at any point either by MPs or their constituents, or any other interested party. Quite the contrary; it was repeatedly stated that the claim for payments was not based on any claim of negligence or unprofessional practice by providers of NHS care – it was based on the precedent established by the payments made to those who contracted HIV following NHS transfusions. Although, therefore, the word "compensation" appears regularly in the record, the claim was, strictly speaking, not a claim for compensation – but a claim for an ex-gratia or discretionary payment, based on the precedent established by the HIV cases.

b) it was clearly open to ministers and officials to enquire whether there was any evidence of negligent or unprofessional care associated with the HCV cases, and this specific question does not appear to have been asked. Both ministers and officials were however clearly looking, over a protracted period, for possible lines of argument which could be used to justify payments to the HCV cases (as was the Haemophilia Society and other interested bodies). It therefore seems reasonable to conclude that if there were an argument based on negligent or unprofessional practice it would have been strongly advanced by the main bodies. To my recollection, it was certainly not the main thrust of the argument being put forward for HCV payments during my time. The argument advanced was instead based on the humanitarian argument and the HIV precedent.

2.126. It is true that Departmental officials, from the Permanent Secretary down, were actively involved in the development and articulation of the Government's policy. It is also true that ministers were engaged in the process at all times and, in accordance with constitutional principles, accepted that responsibility for policy announcements by the Government rested with them and not with officials.

2.127. The process of policy discussion was ongoing and certainly involved probing of alternatives by both ministers and officials. The Government had a clear view but was also willing to consider alternatives. As I stated at para 2.69, in the words of the Permanent Secretary "*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*". That was the essence of the view I set out to the Health Committee on 19 July 1995 following my appointment as Secretary of State and which I maintained, on behalf of the Government, throughout my period of office.

2.128. It reflects my opposition to the principle of no-fault compensation. We recognised that the Government's position was uncomfortable, particularly in view of the exception which had been made in the case of people who had received blood transfusions which were later found to have caused HIV infection, but we continued to believe that all the alternative positions were worse.

Statement of Truth

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

Signed. GRO-C ....

Dated....15/12/2022..