

**HOUSE OF  
LORDS  
QUESTIONS &  
ANSWERS 2000  
- 2007**



1989-1997

## APPENDIX 44

FOOTNOTES 9, 10, 15, 85, 86, 109

24<sup>th</sup> April 2007

**Baroness Masham of Ilton:** My Lords, I thank the noble Baroness, Lady Northover, for this debate on the overwhelming catastrophe affecting so many children across the world. Some years ago, a young child stood up on a stage in South Africa explaining that he had HIV/AIDS as did many other people in his country, and that something had to be done about it. The Government and president of South Africa had denied that fact time after time.

I am a founder member of the All-Party Group on AIDS, which goes back to the early days of 1985-86, when this terrible infection was presenting. That young boy in South Africa who stood up to be counted opened the eyes of many people and had my greatest admiration. I am sure that he touched the hearts of many people across the world.

I once heard a missionary nun say that she knew of a grandmother who had buried 17 members of her family who had died of AIDS. So often, the working members of the family die, leaving orphan children and the very elderly.

I have met children who had **haemophilia** and had been given infected factor 8 imported from America. One father told us at a meeting that he had promised his affected son and his friend, aged about seven, a trip to Disneyland but, because the children had HIV, they were denied entry. How do you think the father felt trying to explain that to the disappointed children?

The noble Lord, Lord Fowler, and I attended a United Nations luncheon a few weeks ago, here in London, which brought together people from many countries interested in trying to do something to combat AIDS. I was fortunate to sit next to a most enthusiastic Minister from Barbados who is running successful music campaigns, getting the message of the dangers of AIDS across through calypsos and songs.

In his Question of Monday, 16 April, the noble Lord, Lord Fowler, said that the number of new diagnoses of HIV had risen by 165 per cent since 1998. I wonder how many of those affected are children. We need a Minister like my luncheon companion who will run dynamic campaigns across Britain to alert those at risk that the problem has not gone away.

**Contaminated Blood Products: Hepatitis C**24<sup>th</sup> May 2006

**Lord Jenkin of Roding** asked Her Majesty's Government:

Whether the files of papers about contaminated blood products which have recently come to light, some of which have been returned to the Department of Health, provide evidence to support the claims of haemophiliacs that their infection with hepatitis was caused by such blood products.

**The Minister of State, Department of Health (Lord Warner):** My Lords, we have established that a number of documents that have been disclosed by the department in the HIV and hepatitis C litigation were held by Blackett Hart & Pratt Solicitors. It agreed to return the papers to our solicitors, who are now considering them with other departmental officials. Advice has yet to be given to Ministers on the significance of the returned files.

**Lord Jenkin of Roding:** My Lords, the files that have turned up came from the archives of more than one firm of English solicitors. Given the substantial volume of documents passed to the department's solicitors—I am told that there are no fewer than 12 big lever-arch files—and the fact that what they have is a small fraction of the material that has been held in solicitors' archives, and given that the department's paper *Self-Sufficiency in Blood Products in England and Wales* was expressly dependent on information that had survived the inadvertent destruction of some 600 of its files, are not there overwhelming arguments for a much more open, independent inquiry into what many regard as perhaps the most serious disaster that has ever happened in the National Health Service?

**Lord Warner:** My Lords, as the noble Lord acknowledges, there are a substantial number of lever-arch files, as he put it, containing documents to be gone through, which is what we are doing. Until we have gone through those files we cannot explain to the noble Lord or anyone else the significance of the documents for the document that we published. We will go through those files as quickly as possible, and I will discuss shortly with my honourable friend the Minister for Public Health how we can give public reassurance and place information from those files where it is significant in the public arena.

**Lord Morris of Manchester:** My Lords, I declare an interest as president of the **Haemophilia Society**. Is my noble friend aware that 1,242 **haemophilia** patients have now been fatally infected by contaminated NHS blood products? In the light

of this awesome reality, is it not disgraceful that officially protected documents of such sensitivity and importance to the haemophilia community were destroyed at the Department of Health? Is it not indisputable now that extra funding is urgently needed to help the afflicted and bereaved, not least widows who today receive no help at all?

Again, has not the case now become unanswerable for an impartial public inquiry into what my noble friend Lord Winston, vice-president of the Haemophilia Society, has called the worst-ever treatment disaster in the history of the NHS?

**Lord Warner:** My Lords, I pay tribute to my noble friend's work on behalf of the Haemophilia Society and its members. He has great persistence and skill in this area. I share his concerns about the position that many of the victims whose blood has been infected by hepatitis C have suffered. As he knows, we have introduced a hepatitis C *ex gratia* payment scheme, which is working. We do not believe that a public inquiry is needed. As I have said on many occasions in the House, we do not think that there is evidence to suggest wrongdoing. We will examine carefully the new files that the solicitors have passed to us and place the results in the public arena as quickly as possible.

**Baroness Barker:** My Lords, what steps will the Department of Health take to ensure the safety of the documents and to ensure that they will not be destroyed inadvertently, as documents that should have been kept for 25 years were destroyed between 1994 and 1998?

**Lord Warner:** My Lords, they were passed from solicitor to solicitor. Government solicitors have professional responsibilities in this area. My colleague Caroline Flint and I will ensure that they are safeguarded, but we need the time to go through the documents to see what their significance is. There are a large number of documents to be gone through.

**Baroness Gardner of Parkes:** My Lords, surely the Minister accepts, though, that the haemophiliacs who have hepatitis got it from blood products. He said that there was no evidence of wrongdoing, but I do not think that anyone is talking about wrongdoing. People would never have given blood products if they had been aware that they were contaminated. It was a most unfortunate thing. As chairman of a hospital that had a major haemophilic unit, I saw such tragic cases, and it should be acknowledged that that was the cause.

**Lord Warner:** My Lords, I do not want to give a science lecture, but we have been over the ground before. The blood infected with hepatitis C was used in circumstances where there was no means of identifying hepatitis C in the blood. The clinical opinion at the time was that hepatitis C was a mild infection, and it took 25 years to find out its seriousness. There was no means of treating the blood in those circumstances. This was blood given to people when it was a matter of life or death whether they received that blood, and we were acting on the best scientific and clinical advice at the time.

**Baroness Finlay of Llandaff:** My Lords, given the distress caused to those who are now bereaved, can the Minister give an assurance that the information gleaned from the review of documents will be communicated not just to the public through the press and media but directly to bereaved families, who may need help in interpreting the information that they receive?

**Lord Warner:** My Lords, the noble Baroness's point is absolutely fair, and I accept it. We will be working with the Haemophilia Society. We will consult it, as we do on many occasions, when we have been through the documents, and we will discuss with it how best to inform individual members of the society and others, where that is appropriate and necessary.

#### Hepatitis C: Contaminated Blood Products

19<sup>th</sup> April 2006

**Lord Jenkin of Roding** asked Her Majesty's Government:

Whether the Department of Health's report *Self-sufficiency in Blood Products in England and Wales*, published on 27 February, is a complete account of the circumstances leading to the infection of National Health Service patients with HIV and hepatitis C due to contaminated blood products.

**The Minister of State, Department of Health (Lord Warner):** My Lords, the report published on 27 February examined key issues around self-sufficiency in blood products in the 1970s and early 1980s. The review was commissioned following suggestions that implementation of what was called the "self-sufficiency policy" in blood products in this period might have avoided haemophiliacs being treated with infected blood products. The report makes it clear that it was based

on surviving documents from 1973, but that self-sufficiency would not have prevented infection of haemophiliacs with hepatitis C.

**Lord Jenkin of Roding:** My Lords, that is all very well, but is the Minister aware that this report, internally produced by his own department, has been roundly condemned by many, including the Haemophilia Society? The society said that the report was,

"a blatant attempt to gloss over the details of the events of the time and even to lay blame at the door of the patients themselves".

Bearing in mind that the department "inadvertently", as the Minister said in response to me in an earlier Question, destroyed all its own files on contaminated blood products and that much new information has recently come to light in the United States, Canada, Ireland and Scotland, is there not now an unanswerable case for a full and impartial public inquiry into what really has been one of the major medical disasters in the National Health Service?

**Lord Warner:** My Lords, I do not accept any of those remarks. We regret that the papers were destroyed in error, which was, I think, explained to the noble Lord in a meeting with the former Permanent Secretary to the Department of Health. I think that it has been explained to him on a number of occasions that there was no deliberate attempt to destroy past papers. We understand that many of the papers were, unfortunately, destroyed, but I have to say that that did not take place under this Government.

I understand the way in which parts of the report may have been interpreted by people from the haemophilia world, and I have enormous sympathy with the circumstances that they face. It is regrettable if it has had that impact on them, but it is a fair and accurate report on what it was asked to do—to identify many of the events and chronology in that period, which were quite complex, and the extent to which the policy of self-sufficiency would have avoided contaminated blood being used by haemophiliacs. The report makes it very clear that the self-sufficiency policy would not have achieved that objective.

**Lord Snape:** My Lords, before we line the pockets of the lawyers in a public inquiry, will the Minister accept that this is a human not a political problem? Did he see the BBC "Breakfast" programme this morning in which a young man was interviewed who had been infected by contaminated blood at the age of five, had been told by his parents at the age of 12 that he had a limited life expectancy, developed full-blown AIDS as a teenager and is still alive in his early twenties after a lifetime of pain and suffering, having been paid only £21,000 in compensation? Will the Government look again at such cases and, regardless of the necessity for a public inquiry, pay adequate compensation to those affected through no fault of their own?

**Lord Warner:** My Lords, I always sympathise with individual cases described by noble Lords. I remind the House that the Government established a hepatitis C ex gratia payment scheme, which has the underlying principle that it is targeted to help alleviate the suffering of people living with inadvertent hepatitis C infection. The reason why we have not gone in for a public inquiry is that there is no evidence of wrongful action on the part of people, which is a different situation from that found in Canada and Ireland. We are continuing to make payments under that scheme. To be fair, the previous government also set up a similar scheme called the Macfarlane Trust in relation to HIV infections through contaminated blood. Both governments have tried to respond to those concerns over the periods that they were in office.

**Baroness Barker:** My Lords, does the Minister accept that the report, which contains no information about what patients were advised at the time and no information about what government policy was on blood donations from high-risk groups, is an unsatisfactory report and will not help to move this policy or this practice forward; nor will it give any help to individuals such as the one mentioned by the noble Lord, Lord Snape?

**Lord Warner:** My Lords, the document is helpful in setting out the chronology and the changes in scientific understanding during this period, which had a considerable impact on policy under successive governments on blood products and their use with haemophiliacs. There was a lot of clinical uncertainty in the early days in identifying hepatitis C. The document sets out clearly those clinical and scientific uncertainties. It gives an extensive 158 references to other documents on which it relied, and we will be looking at a freedom of information request that has been made for putting more of those documents in the public arena. We will look sympathetically at that FOI request.

**Lord Morris of Manchester:** My Lords, I have an interest to declare, not a pecuniary one, as president of the Haemophilia Society. Is my noble friend aware that this in-house inquiry began four years ago with a ministerial prediction that it would report within six months? Do not its errors and omissions—failing even to provide accurate figures on the numbers of patients infected or to acknowledge the 1,240 deaths caused—now totally vindicate the Haemophilia Society's call for an independent public inquiry into the worst-ever treatment disaster in the history of the NHS? Why does the report fail even to mention Mr Justice Burton's landmark High Court ruling on the legal duty to provide clean blood?

**Lord Warner:** My Lords, I accept that the document will not have satisfied everyone, but as I said, it was set up with the main purpose that Yvette Cooper, the Minister who set up the review, described—to identify whether the policy of self-sufficiency in blood products would have prevented the infection of haemophiliacs with hepatitis C through contaminated blood. It deals with that issue along with setting out clearly the chronology, which is complex, as I have said. I recognise the concerns that have been expressed, but we do not believe that a public inquiry is appropriate. There is no evidence of wrongdoing. The report makes that clear, and it gives a set of 158 references in full on which it relied. As I said, we will look sympathetically at placing more of those in the public arena in response to the FOI request that has been made.

#### Hepatitis C: Contaminated Blood Products

12<sup>th</sup> January 2006

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper. In doing so, I declare an interest as president of the **Haemophilia Society**.

The Question was as follows:

To ask Her Majesty's Government whether they are considering giving further help to **haemophilia** patients infected with hepatitis C from contaminated National Health Service blood and blood products and to the widows of those who have died.

**The Minister of State, Department of Health (Lord Warner):** My Lords, as I have said previously, the Government have great sympathy for the pain and hardship suffered by the widows and dependants of those inadvertently infected with hepatitis C. But, as we have made clear repeatedly, the *ex gratia* payments scheme is designed to alleviate the suffering of people infected with hepatitis C and not to compensate for bereavement.

However, I can announce today that my right honourable friend the Secretary of State and her counterparts in the devolved administrations have agreed to extend the period when claims can be made to the Skipton Fund on behalf of deceased patients by relatives or dependants. This means that the relatives or dependants of a person infected with hepatitis C through NHS blood and blood products who died after 5 July 2004, which is when the scheme became operational, will now be eligible to make a claim.

**Lord Morris of Manchester:** My Lords, I am grateful to my noble friend. Is he aware that 1,142 **haemophilia** patients have now died from being infected with HIV and hepatitis C by contaminated National Health Service blood and blood products, making this its worst ever treatment disaster?

My noble friend told me on 11 December 2003 that Ministers,

"do not consider that a public inquiry is justified".—[*Official Report*, 11/12/03; col. 937.]

Is that still their position, despite mounting concern about the handling by in-house inquiries of the important issues raised—as former health Ministers—by the noble Lords, Lord Jenkin and Lord Owen?

Can my noble friend say when the appeal system for the Skipton Fund will be operational; and is he aware that for it to have been ministerially decreed to deny hepatitis C widows the financial help available to HIV widows is widely seen as unjust and morally indefensible?

**Lord Warner:** My Lords, I am well versed in the noble Lord's concerns in this area and I pay tribute to his persistence. But it is important to stress that, despite the Department of Health's decision to make *ex gratia* payments, we do not accept that any wrongful practices were employed in relation to inadvertent infection of blood which led to hepatitis C, and we do not consider that a public inquiry is justified as we do not believe that any new light will be shed on this issue as a result.

I acknowledge that the appeals system has been rather slow to establish the appeals panel, but it is now at the point where the NHS Appointments Commission is about to appoint members to the panel. We know, regrettably, that 57 applicants have indicated that they wish to appeal. I will certainly be pressing for this process to take place as quickly as possible.

**Lord Jenkin of Roding:** My Lords, do the Government intend to publish a review of the whole sad story of contaminated blood products and of the haemophiliacs and others who have been infected with HIV and hepatitis C? Is the Minister aware that after my long perusal last year of a large number of files that passed across my desk on this subject as Secretary of State for Health, I was able to confirm, as I had been warned, that all the papers dealing with contaminated

blood products have been destroyed? How can the review possibly be comprehensive and tell the whole story if the key papers on how these infections reached these patients have been pulped?

**Lord Warner:** My Lords, let me reassure the House that there has been no deliberate attempt to destroy past papers. Officials have established that during the HIV litigation in the 1990s, many papers from that period were recalled. We understand that papers were not adequately archived and were unfortunately destroyed in the early 1990s. Officials have also established that a number of files were marked for destruction in the 1990s. Clearly, that should not have happened. When it was discovered that files had been destroyed, an internal review was undertaken by officials. The results of that will be made known as soon as possible. I know that the noble Lord has been in correspondence with the Permanent Secretary of the Department of Health and I understand that an answer will be sent to him on some of those issues as quickly as possible.

**Baroness Masham of Ilton:** My Lords, I also declare an interest as a vice-president of the Haemophilia Society. Why are we not as generous as Canada in helping those unfortunate people? Can the Minister reassure the House that CJD is not also a problem for those unfortunate people?

**Lord Warner:** My Lords, there is a difference between the position in Canada and in the United Kingdom and it is important to recognise that distinction. The awards being made in Canada follow a class action brought against the Canadian Government. A settlement agreement was reached with the federal government and, as such, the payment structure was based on claims for punitive damages. Subsequent inquiries found that wrongful practices had been employed and criminal charges were laid against the organisations, including the Red Cross Society, who were responsible for screening blood. There was no such wrongdoing in the United Kingdom and it is unfair to compare the two schemes. I will look into the latter point that the noble Baroness raises and write to her.

**Lord Winston:** My Lords, my noble friend uses the phrase "reassure the House", but is not one of the issues here the need to reassure the public, particularly those who feel very threatened when they are offered blood transfusions? Is there not a need for the Government to show care and compassion to these most unfortunate people?

**Lord Warner:** My Lords, the Government have shown care and compassion for those who are infected with hepatitis C. The scheme that is the subject of the Question was introduced by this Government. It was announced in 2003 and we are moving to make payments to people who were alive then and infected with hepatitis C. We have now spent well over £80 million in compensating them to help to alleviate their suffering.

**Lord Addington:** My Lords, do the Government not accept that whatever has been done here, they have given the impression of it being legalistic and slow and not being compatible with the needs of a very similar group? Will the Government give us an undertaking that that will not be the attitude in any future case?

**Lord Warner:** My Lords, let us go back to the basis of the scheme. As I have made clear repeatedly and repeat again today, the infection of people with hepatitis C was inadvertent. Nothing could have been done at the time with the technology available to assess the blood for that level of infection. The blood service did nothing wrong. We as a Government have put in place a scheme to alleviate the suffering of people who were alive after the scheme was announced in August 2003 to provide help for them. We have extended that scheme today in the announcement that I have made, so that the dependants of people who died after the scheme came into operation will also be eligible to make a claim.

**Lord Owen:** My Lords—

**Lord Rooker:** My Lords, we are well into the 25th minute. We must move on.

## Hepatitis C

26 May 2005

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper. In doing so, I declare an interest, not a pecuniary one, as president of the Haemophilia Society.

The Question was as follows:

To ask Her Majesty's Government what further consideration they are giving to providing financial help for the dependants of patients who have died in consequence of being infected with hepatitis C by contaminated National Health Service blood and blood products.

**The Minister of State, Department of Health (Lord Warner):** My Lords, the Government have great sympathy for the pain and hardship suffered by the widows and dependants of those inadvertently infected with hepatitis C. But, as I have previously indicated, our scheme of financial help is designed to alleviate the suffering of those people infected with hepatitis C; it is not intended to compensate for bereavement.

**Lord Morris of Manchester:** My Lords, is my noble friend aware that contaminated NHS blood products have now caused the deaths of 1,137 haemophilia patients, 896 after being infected with HIV and 241 with hepatitis C, making this much the worst treatment disaster in the history of the National Health Service?

My noble friend Lord Winston, vice-president of the Haemophilia Society, has said of HIV and hepatitis C:

"The cause is the same, a virus, and it comes from the same source, blood products".—[Official Report, 5/6/98; col. 672.]

For the wives of those who have died the result too is the same: devastated lives and widowhood.

Why, then, by ministerial decree, are hepatitis C widows denied financial help available to HIV widows? What social justice or morality is there in denying parity of treatment to widows in identically the same tragic position?

**Lord Warner:** My Lords, we have been clear throughout these discussions on hepatitis C, which have been going on for quite a long time, that no negligence was involved and that the scheme was set up to help people who had been infected. It was not a bereavement compensation scheme, no matter how much sympathy we had for the widows and dependants of those infected with hepatitis C. The scheme will provide for around 7,000 people to benefit. I remind noble Lords of the scale of the benefit: a first payment of £20,000 and another £25,000 when the condition is more advanced.

**Lord Roberts of Conwy:** My Lords, in view of what the noble Lord, Lord Morris, said about this being the worst self-inflicted disaster in the history of the NHS, should we not have a public inquiry, particularly into the consequences for victims' relatives, especially widows? There is no point in the Government trying to brush this under the carpet; it is bound to reappear.

**Lord Warner:** My Lords, we are not brushing anything under the carpet. I shall go back over the history: the issue arose under another government, but I am not making a party-political point, because they also behaved responsibly in this area. In 1991, advances in microbiology enabled us to introduce screening of blood donors. At that point the world changed in this area. We are talking about the inability to test for hepatitis C in blood donors before that period.

**Lord Turnberg:** My Lords, I do not think that there is any question of compensation and negligence in this matter. The Government have been very positive in helping those unfortunate individuals who, through no fault of their own, have received blood from patients with AIDS or hepatitis C. The question now is whether the Minister can extend the Government's magnanimity to the dependants of haemophilia patients who have died of hepatitis C.

**Lord Warner:** My Lords, we have enormous sympathy but, as I have said, we have no plans at this point to extend the scheme beyond those infected with hepatitis C.

**Baroness Barker:** My Lords, what is the cost to the families of bringing a claim to the compensation fund, and what is the average time taken between a claim being brought and it being settled?

**Lord Warner:** My Lords, I do not have the details of the time taken. We anticipate that approximately 7,000 people will be entitled to payments under the scheme. So far, just over 3,500 have received payments. Most of those have received the initial payment of £20,000 but just over 350 people have also had the second payment.

**Lord Campbell of Alloway:** My Lords, is this not a classic justification for the introduction of a no-fault compensation scheme, as advocated by Lord Pearson years ago?

**Lord Warner:** My Lords, we will return to some of those issues when the NHS redress Bill comes before the House later in the Session.

**Lord Davies of Coity:** My Lords—

**Lord Corbett of Castle Vale:** My Lords—

**The Minister of State, Northern Ireland Office (Lord Rooker):** My Lords, there is time for both noble Lords, if they are brief.

**Lord Davies of Coity:** My Lords, in view of the concern expressed on this matter, will the Government provide the findings of the internal investigation into haemophilia blood policy, which began in 2002, in order that lessons can be learnt about the safety of blood and blood products?

**Lord Warner:** My Lords, I think that my noble friend refers to the internal review of Department of Health papers going back into the past. It is still ongoing.

**Lord Corbett of Castle Vale:** My Lords, can I tell my noble friend—

**Baroness O'Cathain:** My Lords—

**Lord Rooker:** My Lords, the noble Baroness.

**Baroness O'Cathain:** Thank you, my Lords. I have listened very carefully to the Minister's answers. Is it that the 896 HIV patients who died as a result of contaminated blood products were not infected until after the test was instituted, whereas the hepatitis C people died before the test?

**Lord Warner:** My Lords, they were infected, rather than having died, before the test. That is the issue.

**Lord Corbett of Castle Vale:** My Lords, can I tell the Minister, now, that while the policy of this Government and the previous one is clear, both governments got it wrong? I invite him, the next time this Question comes up in your Lordships' House, to decline to stand up and justify a position where different treatment is given to victims of dirty blood on the basis of whether they got HIV or hepatitis C, as in the case of my former constituent Bob Threackall? Will the Minister acknowledge that contaminated blood was the cause of both lethal infections and that Mrs Threackall and other spouses demand and deserve equal treatment?

**Lord Warner:** My Lords, I sympathise entirely with my noble friend's former constituent. I am always very respectful of his ability to give me instruction. I think that I can set out more clearly and at greater length than we have time for today why we are proceeding in this way.

1  
**Hospital-acquired Infections**

Dec

2004

**Baroness Gardner of Parkes** rose to call attention to government health policies, with particular reference to initiatives designed to reduce hospital-acquired infections; and to move for Papers.

The latest risk is of transmission of new variant Creutzfeld-Jacob disease (vCJD). A number of patients are known to be at risk, as some blood donors developed vCJD and died of it after giving blood. Two recipients of that blood have now developed vCJD. The blood products were used particularly for haemophilia cases. An estimated 6,000 haemophilic patients have received blood products from that plasma.

New variant CJD is a major concern for the future, as there is no blood test for the condition and the incubation period remains unknown. The infectious particles are known as "prions". Fortunately, the risk is still considered low and the risk for haemophiliacs is not considered to be more than 1 per cent above that of other citizens.

An interesting incident arose when one of those haemophilic patients needed a gastroscopy and biopsy of his stomach a month ago. It was performed routinely by the gastroenterologist, who was then told that the brand-new video endoscope, worth about £35,000, must go immediately into indefinite quarantine. That has compromised the hospital's routine endoscopy service to the disadvantage of many thousands who would have been treated during the planned lifetime of the endoscope. The new rule was implemented without warning or consultation with the gastroenterologists. Was it an over-reaction? The use of

recombinant clotting factors for all haemophiliacs would eliminate the risks of transmissible infectious diseases. However, recombinant is still not available for English patients aged over 40.

vCJD

18<sup>th</sup> November 2004

**Baroness Neuberger** asked Her Majesty's Government:

Whether the Health Protection Agency will ensure that all medical and other health practitioners provide guidance and counselling to those young people who have received letters warning of the possible risk of vCJD contamination from plasma products in their National Health Service treatment.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Warner):** My Lords, as I indicated to the noble Baroness on 28 October in my reply to her supplementary question, the notification exercise by the Health Protection Agency is being delivered through the 150 clinicians who are treating people with haemophilia and bleeding disorders, and patients with primary immunodeficiency. These specialist clinicians are known to their patients and are best placed to advise and counsel them and to present this complex information about risk to them, irrespective of their age.

**Baroness Neuberger:** My Lords, I thank the Minister for his reply. I should like to press this a little further. Given the suggestion that some blood tests may shortly become available, and given the implications of variant CJD for younger people, who seem to be more susceptible than older people, I wonder whether the clinicians alone are the right people to deal with this. Could the Government give guidance that counselling should be made available to those who want it, as they have done for people having infertility treatment? Very often, the clinicians do not have the time and sometimes not even the skills to provide the counselling that is needed. Is the Minister prepared to reconsider?

**Lord Warner:** My Lords, the process that has been put in place was agreed with all the patient interests. It was agreed that the information would be communicated by the HPA to the clinicians who would contact the patients, see them, explain matters to them and deal with any requests. There is no screening test available, although research is continuing in this area. We know that children born after 1996 will, in the main, not be involved, as they would not have received implicated products. The decision was taken in February 1998 to place all haemophiliacs under 16 on synthetic clotting products.

**Baroness Trumpington:** My Lords, I was involved in this sort of situation in about 1998. Will the Minister please tell me where the plasma products originate? Are they from this country or another country?

**Lord Warner:** My Lords, this exercise arises from the fact, as my right honourable friend the Secretary of State told another place in December, that a person who had died of variant CJD had received blood from a donor who had died of variant CJD. We are looking at the 176 batches of plasma products that may have had blood from those sources. We are tracing the people who may have received those plasma products, which would almost certainly have come from within this country.

**Lord Walton of Detchant:** My Lords, does the Minister accept that one of the problems with this group of diseases is that the infective agent responsible for both sporadic and new variant Creutzfeldt-Jakob disease is neither a bacterium nor a virus but a prion, a molecule of protein which cannot be destroyed by standard techniques of disinfection or sterilisation? Is he aware that at a recent meeting of the American Neurological Association, Stanley Prusiner, who was awarded the Nobel Prize for his work on prions, reported that a blood test to identify the presence of these agents in blood is likely to be developed within the next two years?

**Lord Warner:** My Lords, I always bow to the noble Lord's scientific knowledge in this area. I am aware that there is optimism in this regard, and I know that the Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation is looking at many of these issues.

**Baroness Masham of Ilton:** My Lords, how can BSE in cattle transfer to CJD in people? What dialogue and co-operation is there between Defra and the Department of Health?

**Lord Warner:** My Lords, this is an extremely joined-up government and the co-operation between Defra and the Department of Health is unparalleled. There is a rather long and complicated answer to the noble Baroness's question and I will write her a suitable letter.

**Baroness Gardner of Parkes:** My Lords, is the Minister aware that a television programme this morning showed that CJD has been transmitted through a family by inheritance? Is that a new aspect to be concerned about or is it a fairly rare incidence?

**Lord Warner:** My Lords, I did not see the television this morning, but I will look into that particular case and write to the noble Baroness.

**Earl Howe:** My Lords, what research has been done to test the hypothesis that variant CJD can be transmitted through blood transfusions?

**Lord Warner:** My Lords, this issue is being looked at actively by the Advisory Committee on the Microbiological Safety of Blood and Tissues. I am not sure of the detail of how far it has got in that research, but I will check and write to the noble Earl.

vCJD

28 Oct 2004

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper. In doing so, I declare an interest, not a pecuniary one, as president of the *Haemophilia Society*.

The Question was as follows:

To ask Her Majesty's Government how many people have already been warned or could eventually be warned by the Department of Health that they may be at risk of developing vCJD as a result of National Health Service treatment.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Warner):** My Lords, in England 15 recipients of whole blood were notified in December 2003 of their possible increased risk of variant CJD. For recipients of plasma products, the patient notification exercise started on 21 September, and will run for a few months. Patient records are being examined currently. Until completed, it is not possible to say how many more people will be notified as a result of this exercise.

**Lord Morris of Manchester:** My Lords, I am grateful to my noble friend. Is he aware just how devastating this deadly further threat has been to the *haemophilia* community, already mourning 1,000 deaths from HIV and hepatitis C infection by contaminated NHS blood products, and both deeply hurt and offended by the total denial of any financial help for families bereaved by hepatitis C infection?

We are told nobody is to blame for the disaster. But how can this be validated, except by an independent inquiry and how, without one, shall we ever know whether the risk of vCJD would have been reduced had the safer recombinant treatment been available for all *haemophilia* patients in 1995? Is there not now a compellingly urgent need for a wide-ranging public inquiry into this worst-ever treatment disaster in the history of the NHS?

**Lord Warner:** My Lords, I recognise what my noble friend says. This exercise causes further anxiety for a group of people for whom everybody in this House has enormous sympathy. We have undertaken this tracing exercise in full consultation with the *Haemophilia Society*, to which I pay tribute for all its help. I am afraid that we must accept that there is a great deal of scientific uncertainty about variant CJD and no consensus among experts on assessing the risks to those patients who have received potentially contaminated—I emphasise "potentially"—batches of plasma. The Government have been transparent in their actions and in putting information on variant CJD in the public arena and before Parliament, and we will continue to do so. Wrongful practices have not been employed; we do not believe that a public inquiry is justified.

**Lord Walton of Detchant:** My Lords, does the Minister accept that the agent responsible for the transmission of both sporadic and new variant CJD is neither a bacterium nor a virus but an abnormal molecule of protein called a prion? Does he therefore accept that the presumed discovery of transmission of that agent by blood transfusion was both unexpected and alarming? No diagnostic or screening test exists at present, although recently Stanley Prusiner, Nobel prize-winner for his work on prions, suggested that one may be impending. Nevertheless, is it not crucial, as the noble Lord, Lord Morris, has said, that recombinant factor 8 should be made widely available throughout the NHS for all *haemophiliacs* sufferers?

**Lord Warner:** My Lords, I am grateful to the noble Lord for his remarks, given his great expertise in this area of medicine and science. It is certainly true that, as yet, there is no blood test for variant CJD, let alone one that could detect the disease years before symptoms develop. We accept the need to make progress on recombinant products but we will do so in an orderly way. I can write to the noble Lord with details of our progress.

**Lord Roberts of Conwy:** My Lords, what sort of financial assistance is available in those 1,000 cases to which the noble Lord referred? Obviously, many families will have been devastated by those deaths.

**Lord Warner:** My Lords, this Question is about variant CJD and a tracing exercise. The noble Lord, Lord Morris, introduced the issue of hepatitis C, which we have debated in this House on several occasions but that is outside the scope of this Question. I will write to the noble Lord with details on hepatitis C and the other issues that he mentioned.

**Baroness Neuberger:** My Lords, in agreeing that, obviously, considerable distress has been caused to all those who have received the letters, will the Minister now consider whether something particular should be done for the younger people who may be affected? There is growing evidence that younger people are more susceptible to variant CJD than older ones. Growing evidence, particularly from some French scientists, shows that of the cases in the UK a disproportionate number of younger people and teenagers have been affected. Is the Minister prepared to consider specific counselling for younger people among those who have received a letter warning them of the possible risk?

**Lord Warner:** My Lords, the exercise for tracing people who, I re-emphasise, are potentially at risk of having received possibly contaminated plasma products is being conducted through the Health Protection Agency and, perhaps more significantly, through the 150 clinicians who are treating those with *haemophilia* and bleeding disorders. They are best placed to advise their patients—they know their patients—on how to respond and to present this information of risk to them. I emphasise that we are talking about products that are potentially contaminated. The 176 batches of plasma products that have been traced are all the result of further dilution of any contaminated blood that has been injected into those batches: It makes risk assessment in this area extraordinarily difficult. There is no consensus among experts on the risk.

**Earl Howe:** My Lords, the Minister will know that, as part of the Government's precautionary approach, it was decided that all people who have received a blood transfusion since 1980 are banned from giving blood. What official assessment has been made of the effect of that ruling on the number of people now able to donate blood, and is there any threat to blood supplies?

**Lord Warner:** My Lords, taking a proportion of donors and potential donors out of the supply chain has some impact. But the Government have gone to great lengths to ensure that we have an adequate blood supply. One of the measures that we have been taking, in full consultation with the medical and other health professions, is how we make best use of the blood supply that we have. Over the years, there has been concern that we may have inappropriately used some of our blood supply. We are taking measures with experts to ensure that our available blood supply is used efficiently.

#### **Blood Donation and vCJD**

**9<sup>th</sup> September 2004**

**Lord Warner:** My right honourable friend the Secretary of State for Health has made the following Written Ministerial Statement today.

Following my Statements to the House on 17 December 2003 and 16 March 2004 concerning variant Creutzfeldt-Jakob disease (vCJD) and blood, I wish to provide an update on some further developments in this area.

My Statement on 17 December 2003 informed the House of the first case of possible transmission of vCJD via blood transfusion and the precautionary actions taken. Those actions included measures to protect future blood supplies and contacting recipients of blood from donors who subsequently went on to develop vCJD. A further Written Statement on 22 July 2004 indicated a second case of possible vCJD prior transmission via blood transfusion had been confirmed.

I also made reference in December to the fact that other patients, including people with *haemophilia* and other bleeding disorders, would have received plasma products before they were sourced from the United States of America. Although there are now two reports of possible transmission of vCJD via blood, the risk of transmission via plasma products, which will have been derived from large pools of plasma donated from many thousands of people—and therefore heavily diluted—is uncertain. But it cannot be excluded. The CJD Incident Panel (CJDIP) were asked to advise on a case-by-case basis (having adopted a highly precautionary approach) which recipients of plasma products will need to be contacted. This advice has been received and a programme of action has been agreed.

In June 2004 the Health Protection Agency (HPA), on behalf of the CJD Incident Panel, reported on an assessment of the risk associated with each batch of product and advised my department on: a) which patients needed to be assessed and possibly subsequently contacted, and b) managing the possible risk to public health of those patients.

In the light of these assessments, the HPA is today initiating a process to notify relevant patients of these developments. The HPA are sending information to clinicians to enable them to trace particular plasma products. The clinicians will then notify any patients identified as 'at risk' as a precaution. Any patients affected should expect to be contacted by clinicians later this month.

Aside from patients with **haemophilia** or other bleeding disorders, the other main group of patients who may have received significant amounts of affected blood products are patients with primary immuno-deficiency (PID).

Throughout this exercise we have been concerned to ensure that the results of the risk assessment are communicated to patients by the clinicians responsible for their day to day care, so that appropriate supporting information can be provided.

Further details about the risk assessment exercise will not be disclosed until after patients are informed of the outcome. I will make a further Statement at a later date, if necessary.

### Hepatitis C

25<sup>th</sup> March 2004

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper. In doing so, I declare an interest, not a financial one, as president of the **Haemophilia Society**.

The Question was as follows:

To ask Her Majesty's Government whether they will reconsider their decision to exclude the widows of patients infected with hepatitis C by contaminated National Health Service blood and blood products from help under the ex gratia payments scheme.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Warner):** My Lords, the Government have great sympathy for the pain and hardship suffered by the widows of those inadvertently infected with hepatitis C. However, it has always been clear that the ex gratia payments scheme known as the Skipton Fund is not designed to compensate for bereavement. As such, there are no plans to reconsider that decision.

**Lord Morris of Manchester:** My Lords, while again I acknowledge the breakthrough achieved by John Reid's announcement of the scheme, can my noble friend say what it will cost and from which budget or budgets? Meanwhile, how can any of us justify excluding widows? Is not theirs the cruellest loss, having seen a husband and father die what my noble friend Lord Winston describes as a,

"slow, agonising death from cirrhosis or liver cancer due entirely to contaminated NHS blood products"?

Infected with hepatitis C, they were denied life assurance, and the onset of liver disease forced many into early retirement, so impoverishing their families. Where is the natural justice in including widows in the existing ex gratia scheme for HIV infection, while excluding them from this scheme? And where is the morality in denying parity of treatment to widows in identically the same tragic position?

**Lord Warner:** My Lords, again I pay tribute to the work done by my noble friend and the **Haemophilia Society** in pursuing the issue. But the underlying principles of the scheme that has been announced is that it should be targeted to help to alleviate the suffering of people living with inadvertent—I stress, inadvertent—hepatitis C infection. The fund is not designed to compensate for refusal of cover, loss of earnings or bereavement. I understand the problems that my noble friend has outlined, but my understanding is that hepatitis C does not automatically preclude someone from gaining life assurance.

It is difficult to predict the cost of the scheme and the number of people who will benefit, but our best estimates are that between 6,000 and 7,000 people will benefit from the scheme. I can reassure my noble friend that the department will honour all valid claims.

**Lord Addington:** My Lords, does the Minister not agree that we have heard in the past a great deal of resistance to our making any payment to those infected with hepatitis C in very similar terms to the resistance we have heard about giving it to families of those who have died as a result of the infection? Under those circumstances, would it not be sensible to consider making a payment to those who are suffering financially in exactly the same way?

**Lord Warner:** My Lords, I am in danger of repeating myself. We have made absolutely clear the basis of the scheme: to alleviate suffering among those who are living and have suffered as a result of the infection. It is not a compensation scheme. All credit is due to my right honourable friend the Secretary of State for Health, who decided last summer to bring the scheme into operation.

**Earl Howe:** My Lords, when the noble Lord, Lord Morris, asked a similar Question some time ago, the Minister commented that the equivalent schemes for compensating haemophiliacs in Canada and the Irish Republic, which are much more generous than the scheme that the Government have now proposed, were based on the fact that the governments of those countries had accepted liability for the damage that took place. Can the Minister confirm the Answer that he gave before, because my information is different from his?

**Lord Warner:** My Lords, I am grateful to the noble Earl for giving me the opportunity to clarify the issue. My understanding of the position in Ireland, which has been corroborated by officials in the Department of Health and Children in Dublin since my last utterances on the subject in the House, is that the Irish Government set up their hepatitis C compensation scheme following evidence of negligence by the Irish Blood Transfusion Service. A judicial inquiry, the Finlay report, found that "wrongful acts were committed". It is important to stress that the blood services in the UK have not been found to be similarly at fault. Compensation is therefore being given in very different, specific circumstances in Ireland that do not apply in the UK. I do not believe that the Irish scheme creates any precedent for us.

The awards being made in Canada follow a class action brought against the Canadian Government. The compensation from the federal government is limited to those infected between 1986 and 1990. Subsequent inquiries found that wrongful practices had been employed, and criminal charges were made against organisations including the Canadian Red Cross Society. Those conditions in Ireland and Canada do not apply in the UK.

**Lord Ackner:** My Lords, firstly I appreciate that, whenever I hear the Government express sympathy, I irritate them by pointing to the millions of pounds a year spent on victims of violent crime for whom the Government have not the slightest responsibility, whereas in this case the Government actually injected the substance. But for the fact that negligence must be proved, they would be liable.

Secondly, will the Minister explain, not why damages for bereavement are not provided, but why no damages for loss of dependency are provided? That is a separate head of damage which, if there were liability, would have had to be accepted by the Government.

**Lord Warner:** My Lords, I always bow to the noble and learned Lord in his knowledge of the law, but it is not my responsibility to answer for criminal compensation schemes. I am sure that my noble friend Lady Scotland will read his comments with interest. A line must be drawn somewhere on eligibility for this scheme. As I said in answers to previous supplementary questions, there was no case of negligence by the National Blood Service. The lines have been drawn on the basis that I have explained, and there is nothing more that the Government can say on this issue.

**Lord Donham:** My Lords, the Minister cannot say that it is not his department that is concerned. The noble Lord answers in this House for Her Majesty's Government.

**Lord Warner:** My Lords, I confirm that I answer for Her Majesty's Government, but the subject of the criminal injuries compensation scheme is outside the remit of the Department of Health.

**A noble Lord:** My Lords—

**Lord Warner:** My Lords, may I finish? The subject is also wide of this Question.

**Hepatitis C**

**5<sup>th</sup> February 2004**

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper, and declare an interest—not a pecuniary one—as president of the Haemophilia Society.

The Question was as follows:

To ask Her Majesty's Government how they arrived at the scale of ex gratia payments for patients infected by contaminated National Health Service blood products with hepatitis C, proposed by the Secretary of State for Health on 23 January; and why the widows of those who have died are excluded from help.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Warner):** My Lords, the level of payments was decided after consideration of a number of independent sources. Those included the payment schemes of the Macfarlane and Eileen Trusts, the reports of the Scottish Executive's expert group and the Hepatitis C Working Party to the Haemophilia Society. The underlying principle behind the ex gratia payments is to help alleviate the suffering of people living with inadvertent hepatitis C infection. That is where the money available has been concentrated. These payments are not compensation for bereavement, although we recognise the pain and hardship suffered by widows.

**Lord Morris of Manchester:** My Lords, while I am grateful to my noble friend and, more especially, to John Reid, for the major reversal of policy in setting up a payments scheme, are Ministers aware of the scale of the disaster that has befallen the haemophilia community: that more than 1,000 people with haemophilia have already died from contaminated NHS blood and blood products; that many others are now terminally ill and waiting to die; that the help the scheme proposes is barely one-tenth of what is paid in Ireland; that excluding widows whose lives have been devastated by the disaster, causing them added distress and double despair, is seen as a total disgrace by the Haemophilia Society; that the society insists that there has been no meaningful consultation about these, among other deeply disturbing defects in the scheme, and that such consultation should take place forthwith?

**Lord Warner:** My Lords, this Question gives me the opportunity to pay tribute to the work done by my noble friend in his tireless efforts on behalf of the Haemophilia Society and the wider haemophilia community to put this item on the agenda. As he rightly says, my right honourable friend the Secretary of State has made a big gesture towards the concerns of that community, which we all recognise, and the hardship that has followed. It is important to distinguish between the scheme and that in Ireland, where public inquiries and criminal charges affected the basis of the scheme.

There has been strong dialogue with the Haemophilia Society. It has been involved in meetings with Ministers and departmental officials. It has a nominated representative to sit on the group of experts advising on the trigger point for the scheme's second payment and, at its behest, that representation was recently increased. We will continue to consult it fully on development of the scheme.

**Lord Walton of Detchant:** My Lords, is the Minister aware of emerging research evidence suggesting that a modified preparation of Interferon may prove to be an effective treatment for hepatitis C, with the hope that there may ultimately be a means of eliminating the virus? If that is proven, do the Government want such treatment made available under the NHS? Or will they at least promote research into the use of that preparation in treatment?

**Lord Warner:** My Lords, the National Institute for Clinical Excellence has published guidance on the use of combination therapy for the treatment of hepatitis C. We have provided additional funding and placed statutory obligations on the NHS to implement NICE's recommendations, so that clinical decisions made by doctors involving NICE-recommended treatment or drugs can be funded. I will look into the further points that the noble Lord made, but that is the current position for therapies in that area.

**Lord Addington:** My Lords, do the Government accept that we have been hearing Questions on this subject for a long time? The impression that many of us have gained from listening to the Answers is that the Government have moved slowly and only when pushed. They seem to have been hiding behind a curtain of legal restriction, and have not been addressing the point that people have died and are dying through no fault of their own, but through government action. Do the Government accept that, in future, quicker action should be taken and that there should not be this ritual dance around legal niceties?

**Lord Warner:** My Lords, I do not think that we are engaged in a dance around legal niceties. We have been working with the Haemophilia Society and other interests to produce a workable scheme, which has as its basis an initial payment of £20,000, with a further £25,000 if cirrhosis develops or if a claimant has liver cancer or has had a transplant. We are now trying to ensure that we can bring the scheme into operation as quickly as possible—wherever possible, from April this year.

**Lord Campbell of Croy:** My Lords, can the Minister tell the House how many patients are still alive and how many widows there are now to be considered?

**Lord Warner:** My Lords, I do not know the precise number of widows. I will look into the matter and write to the noble Lord; but more than 5,000 or 6,000 people may be beneficiaries of the scheme.

**Baroness Gardner of Parkes:** My Lords, will the Minister confirm that that benefit will be tax free and that people on social security will have a total disregard of that amount?

**Lord Warner:** My Lords, I am pleased to tell the noble Baroness that, subject to the necessary amendments to social security legislation, the payments will be fully disregarded for the purposes of social security benefits. A similar disregard has been secured for tax assessment.

**Lord Ackner:** My Lords, are widows being included? If not, what is the philosophy behind the decision to exclude them?

**Lord Warner:** My Lords, I tried to cover that point in my first Answer. These payments are not compensation for bereavement, although we recognise the pain and hardship suffered by widows. They are payments to alleviate the suffering of people who are living with inadvertent hepatitis C infection.

**Lord Roberts of Conwy:** My Lords, the noble Lord mentioned the Macfarlane Trust. Am I right in thinking that that fund covers widows? It certainly does not seem obvious that there should be any difference between the Government's proposals and the Macfarlane Trust scale. Secondly, have the Government compared their proposals with the scale available, for example, in Canada, which is much more generous?

**Lord Warner:** My Lords, the awards that were made in Ireland and in Canada followed public inquiries or criminal charges which established that wrongful practices were employed. The payment structures of those schemes were therefore based on claims for punitive damages. We do not acknowledge any such wrongdoing in England, so it is not fair to make a comparison between those schemes. The Macfarlane Trust will be involved in the administration of this scheme, but there are significant differences. The Government's policy is as I set out in the Answer to my noble friend.

#### **Hepatitis C Compensation Scheme**

**26<sup>th</sup> January 2004**

**Lord Warner:** My right honourable friend the Secretary of State for Health has made the following Written Ministerial Statement.

The department announced in August of last year the setting up of an ex-gratia payment scheme for people infected with hepatitis C from National Health Service blood or blood products. Since that announcement, work has progressed on the detail of the scheme.

The UK scheme will award eligible claimants with initial lump sum payments of £20,000 to all those who now have hepatitis C from blood or blood products, with a further £25,000 being awarded when people reach a more advanced stage of illness.

We feel that these are fair and reasonable payments and hope that they will help to alleviate some of the problems people who have been affected in this way are experiencing.

Work is ongoing to set up the independent body that will administer the scheme and to introduce the necessary legislation so that people will not lose their social security benefits as a result.

In the course of negotiations we have been able to define a further level of detail on eligibility and scheme administration which will be advantageous to claimants. In particular, bureaucracy will be minimised for people making a claim, in recognition that it will be difficult for some people to gather evidence from 20 years ago.

The scope of the scheme has also been extended to include people who have cleared the virus as a result of treatment and to those infected as a result of the virus being transmitted from someone who was infected from blood or blood products. The scheme will also consider people who were infected with HIV as well as hepatitis C in the same way as those only infected with the hepatitis C virus.

Work is progressing on finalising the application process for awards and setting up the independent body that will administer the scheme. Organisations such as the Haemophilia Society and Hepatitis C Trust will be fully involved in that work to help to ensure that the procedures are as user-friendly as possible.

We will work with the relevant organisations to ensure that claimants know what to do to make an application.

## Hepatitis C

11 December 2003

**Lord Morris of Manchester** rose to ask Her Majesty's Government what developments there have been since they announced in August an ex gratia payment scheme for people infected with hepatitis C by contaminated National Health Service blood products.

The noble Lord said: My Lords, I beg leave to ask the Question in my name on the Order Paper and, in doing so, I have an interest to declare, not a pecuniary one, as president of the *Haemophilia* Society.

I am grateful to all noble Lords who will be speaking in this evening's debate and I am delighted that my noble friend Lord Warner is responding for the Government.

It is one of the most endearing charms of this House that one never knows who is going to turn up here next. It was almost 30 years ago that I first met my noble friend Lord Warner; and I was extremely glad to welcome him to this House. When we met in 1974 he was a young and highly promising civil servant at the former Department of Health and Social Security in which, although my responsibilities as the first Minister for Disabled People extended all across Whitehall, I was based for more than five years. He was often involved then in helping to arrange for other officials to put together draft parliamentary speeches for his Minister to consider; and naturally I much look forward to hearing him make a speech of his own this evening. I know he will do so with all his customary decency and social concern.

This debate is about a small and stricken community of disabled people for whom acquaintance with grief—recurrent and abject grief—is an inescapable fact of daily life. So too is the burning sense of injustice among them that, while conceding the case for special help for *haemophilia* patients infected with HIV by their NHS treatment, successive governments have resolutely refused any such help for hepatitis C infection.

Already disabled by a rare, life-long bleeding disorder that requires continuous medical treatment, people with *haemophilia* have twice been infected en masse by contaminated NHS blood products. Of a patient group numbering only 5,000 nationally, 95 per cent were infected with hepatitis C and one in four with HIV. Thus many in the *haemophilia* community were doubly infected and left at double risk of contracting a life-threatening illness and in double despair. Of those infected with HIV, over 900 have since died of AIDS-related illnesses and 232 more lives have been lost to cirrhosis and liver cancer due to hepatitis C infection.

Now the same small community faces the hideous threat of variant CJD. This is not a theoretical risk. More and more *haemophilia* patients are being officially informed that blood products from donors since diagnosed with vCJD were used in their NHS treatment. Imagine the alarm and anguish of parents who learn that their child has been put at this grave further risk. Or that of the adult who has already been infected with HIV and/or hepatitis C and must now try to cope with not knowing whether he may also have been infected with vCJD. Their distress is made no easier by disclosures in recent parliamentary replies to me that the Department of Health does not even know how many *haemophilia* patients have been given blood from donors with vCJD and has no plans to find out.

Yet there is a crucial difference between this debate and all the others I have initiated for the *Haemophilia* Society, both here and previously in the House of Commons, over the past 15 years. Before previous debates, I was told that I was banging my head against a brick wall in asking for parity of treatment for people infected with HIV and hepatitis C—and afterwards, simply, "We told you so". But John Reid, within months of his appointment as Secretary of State for Health and much to his honour, signalled a fundamental reversal of policy with his announcement on 29th August of an ex gratia payments scheme for hepatitis C infection.

I congratulate my right honourable friend and the Government on bringing new hope to the *haemophilia* community. My principal concern this evening is to ensure that the pledge of 29th August is implemented with social fairness and full regard to the levels of financial help already given to identically affected patients and dependants in other countries, many of them with economies less strong and much poorer than ours, across the world.

That is the task facing us now and much the best way of tackling it successfully—I am of course aware of the meetings Melanie Johnson and officials have had with the *Haemophilia* Society—is for the Government to stay in close and continuous rapport with the *haemophilia* community. After all, they know most about the history of the case and the realities of life for those infected and their dependants.

I refer to the history of the case because people unaware of the suffering that living with *haemophilia* can inflict find it hard to understand how deep is the sense of injustice in the *haemophilia* community. To have been infected with deadly

viruses by the NHS treatment on which they rely vitally for survival, with no official apology or explanation, is but part of the case. They find it disgraceful that in this country, unlike Canada, Japan, Ireland and France, there has been no official inquiry. Questions remain unanswered as to how so many patients came to be infected and—recalling the disclosures of the noble Lord, Lord Owen, as a former health Minister—why more was not done sooner to prevent this worst ever treatment disaster in the history of the NHS.

They point out that if a tragedy on anything like that scale occurred today, an official inquiry would most certainly be held, as rightly happened after the Paddington train crash and the sinking of the "Marchioness". Serious as the consequences of these tragedies were, they did not begin to compare in scale with the loss of life caused by the contaminated NHS blood and blood products disaster. Nor has the wilful act of dividing the victims of that disaster, not on the basis of the effects of their infection but simply its classification, any parallel in the approach to other disasters here in Britain, or indeed anywhere else in the world.

How can anyone possibly justify the decision to give financial assistance to patients infected with HIV by their NHS treatment, but not to those fatally infected by the same route with hepatitis C and bereaved families? Yet that remains the position until John Reid's pledge is implemented. The profoundly moving story of three brothers explains its stark inhumanity.

All three brothers inherited **haemophilia**. Two were infected with HIV by their NHS treatment and died of AIDS-related illnesses. They received financial help from the Macfarlane Trust, set up and funded by the then government in 1989, and were able to make provision for their families. The third brother escaped HIV infection but was infected with hepatitis C, also by contaminated blood products used in his NHS treatment, and died of liver failure. For him there was no financial help. He went to his grave unable to make any provision for his family.

Each of the three brothers had become terminally ill and died from the same cause: contaminated NHS blood and blood products. But one was denied the help given by a government-funded trust to the other two. That contrast in treatment not only suggests but shouts of injustice.

The setting up of the Macfarlane Trust was an official acceptance of moral responsibility. There was then, and is now, exactly the same moral responsibility for loss and hardship among those infected with hepatitis C. But 15 years on, they still await parity of treatment with patients who were infected at the same time and by the same route.

Some in Whitehall have suggested that infection with HIV is in a different class of seriousness from hepatitis C infection. But let them try telling that to my noble friend Lord Winston, himself a vice-president of the **Haemophilia Society**, whose standing as a doctor is respected all across this House. Speaking in a previous debate of mine here, my noble friend said:

"One cannot escape the terrible fact that death by liver failure or liver cancer is a particularly horrible end. There is a slow inexorable decline . . . severe pain that is quite intractable. The end is a mixture of mental confusion and finally coma".

He added:

"There is no difference between HIV and hepatitis C . . . The cause is the same, a virus, and it comes from the same source, blood products".—[Official Report, 5/06/98; col. 672.]

The Department of Health's official position since 29th August has been that the implementation of John Reid's pledge is under urgent consideration and that the design of the ex gratia payment scheme has still to be decided. But as all of us know, the grape vine flourishes among people in pressing need when month after month goes by without any authentic guide to the thinking of those making decisions of huge significance to them.

Of course, money can never compensate for the deaths of husbands, fathers or brothers; nor can it restore the health that infected patients have lost. But it can help bereaved families and assist in meeting the onerous financial effects of living with a life-threatening virus, which research by the **Haemophilia Society**, made freely available to the Department of Health, has so ably and conclusively documented.

To assist my noble friend in replying to the debate, I want now to set out concerns and fears in the **haemophilia** community about what is being considered. First, there is widespread fear that the scheme, when it is announced, will be based on proposals made by the Scottish Health Minister, Malcolm Chisholm, earlier this year in the only statement to date about ministerial intentions on the details of implementing an ex gratia payment scheme. If so, the amount suggested will fall far short of the recommendations of the expert group that he himself set up to study and report on the issues, under the chairmanship of Lord Ross, with which I had the pleasure of discussing at length comparative provision and the problems and needs of those infected from my experience both as a Minister for Disabled People and president of the **Haemophilia Society**. That experience left me with the highest regard for and indeed in admiration of the care and thoroughness, objectivity and moral integrity of Lord Ross and his colleagues.

As my noble friend will know, Lord Ross's expert group recommended a payment of £50,000 for each infected person, with further amounts for those who develop cirrhosis, while the Health Minister has seemed content to pay only £20,000 to each infected person. My noble friend will be aware that the Haemophilia Society has calculated the costs of more comprehensive provision that includes a loss-of-earnings element, with payments linked to the stage of disease progression and based on the scheme set up by the Canadian Government. That averages some £140,000 per person. There is very serious concern also that, under Malcolm Chisholm's proposals, nothing would be provided for the 232 bereaved families of those who have died from hepatitis C infection—nothing at all—which would cause grievous hurt throughout the haemophilia community.

Again, there is concern that nothing may be provided for those who have cleared the virus, after long years of illness and sustained pain and suffering. It is feared too that the scheme will offer nothing to people with HIV and hepatitis co-infection, who may already have received some help for their HIV infection. Yet there is clear medical evidence that co-infection poses the greatest risk of all.

The haemophilia community hopes to hear assurances from the Minister this evening that these fears are unfounded. If not, it insists, the scheme will be gravely flawed and disfigured by excluding people in the greatest need and perpetuating inequities. I very much hope that will not happen and also that there is no substance in the suggestion that 29th August, 2003 will be used to determine who will and will not be eligible for financial assistance, so that the dependants of a victim who died the day before would be excluded from help. That would mean that a victim who died on 28th August would be covered and one who died on 30th August would not. Such an arrangement would lack compassion, logic and equity. How can it possibly be justified when the suffering of their bereaved families is the same?

There are many widows who have been waiting for help in recognition of the death of their partners who would find it inconceivable that they could be excluded. How much harder will it be for them to accept if they are told that their exclusion is simply a matter of the date on which their loved one died?

Yet it is not only the bereaved who could be affected in this way. I give another example of what many haemophilia patients fear could happen—that of a person infected with hepatitis C who suffers all of the effects of the disease, with progressive liver damage, but after a long and painful course of treatment manages to clear the virus. Again, if his treatment took place before 29th August, he too, it is feared, could receive nothing, while if his treatment concluded after 29th August—meaning that he still had the virus on that date—he could receive a payment. How could such double standards be justified and how can they be avoided if an arbitrarily selected date is set?

These are not hypothetical examples. The Haemophilia Society has case histories of members that show exactly the anomalies that could arise. One is that of two brothers with severe haemophilia, both of whom I met at the Carpet of Lilies event held by the Haemophilia Society here in Westminster last week. One had managed to clear the virus after extremely painful and protracted treatment and it is feared that he could receive nothing, while his brother, still gravely ill with the virus, would receive a payment. Again, how could this be justified?

That Ministers have said that the final design of the scheme is not yet decided provides grounds for hope. It must mean that it is not too late for consideration of the concerns that I have put to my noble friend this evening. And I am sure he would agree that much the best way of dealing with anomalies is not to correct them after damage has been done, but to anticipate and prevent their occurrence. Meanwhile let me again assure my noble friend of my indebtedness to John Reid for his decision to introduce a payments scheme and that I wish for nothing more now than that the long years of campaigning for justice for the haemophilia community are nearing conclusion. My regret is that it should ever have been necessary to campaign for them on the issues that I have raised in debate after debate, both here and in another place. For in none of the many parliamentary campaigns I have been closely involved in over 39 years in Parliament—even thalidomide and those more than 30 years ago for statutory recognition of dyslexia and autism—have I had so strong a sense that no campaigning should have been necessary to right such wrongs. Enormous cross-party backing has been given in both Houses of Parliament; and the issue of parity of treatment for HIV and hepatitis C infection, in particular, is everywhere seen not as one of Right and Left, but of right and wrong.

That is why, if campaigning has to go on, I am in no doubt—nor should anyone else be in any doubt—that go on it will until right is done.

**Lord Clement-Jones:** My Lords, perhaps I may start by congratulating the noble Lord, Lord Morris, on initiating the debate and, in particular, on the timing of the debate. It gives us an opportunity to explore the details of the Government's new financial assistance scheme and at least to challenge the Government to give some details, and to give them food for thought when formulating the scheme.

In many ways, it is regrettable that we have had to have so many debates over the years. I have lost count of the number of debates initiated by the noble Lord, Lord Morris, in which I have taken part during the past six years. He should take considerable comfort from the fact that it is largely as a result of persistence from him and the Haemophilia Society that the Government have now decided to introduce a financial assistance scheme. I welcome that at least a scheme—it may not be wholly satisfactory—is certainly in the offing.

The bald statistics do not give the full picture. As the noble Lord, Lord Morris, said, approximately 5,000 people with haemophilia in the UK were infected with the hepatitis C virus in the 1970s and early 1980s. Medical estimates are that up to 85 per cent of those people develop chronic liver disease: I believe that well over 200 people have now died from liver cancer and liver disease arising as a result of infection.

In common, I am sure, with other noble Lords, I have had considerable correspondence on the subject. The statistics give no real idea of the absolute misery of the individuals infected by hepatitis C, the effect that it has on their families, or the misery of their deterioration and, in many cases, death.

I recently received a very poignant letter from a lady who sent me the diary of the last few weeks of her husband's life. It makes extremely harrowing reading. She wrote:

"The way of his going is still with our children and myself".

That was in 1998.

"End liver failure is a terrible death, time does not heal and it never will".

I believe that the noble Baroness, Lady Andrews, has seen extracts from the diary, which makes very harrowing reading. The noble Lord, Lord Morris, was right when he talked about recurrent and abject grief. That cannot be compensated in money terms, but it is incumbent on us at least to obtain some kind of financial compensation for what has happened to them. After all, they are the innocent victims of blood contamination. It is hugely important that the Government make sufficient payments to recompense all those haemophiliacs who, if they have not already done so, will develop debilitating liver diseases, as well as to their families who also suffer from the effects.

The noble Lord, Lord Morris, talked about the absolute contrast with the way in which the Macfarlane Trust was set up in 1989, where, to date, £90 million has been given by way of compensation. As the noble Lord has pointed out in previous debates, no equivalent provision has been made for those who contracted HCV.

I suppose that the Government's real case has been based on an unwillingness to breach a general rule that compensation is given only where the NHS is at fault. That was certainly the line taken when we debated this matter last March. But a complete exception was made to that rule—whether it was called financial assistance or something else; in substance it was compensation, whatever its legal status—in the case of sufferers from HIV transmission. However, the same has not been done for those with HCV.

As the noble Lord, Lord Morris, pointed out, that contrasts with the behaviour of many other governments, whether in the EU, Japan or Canada. Not only have they instituted schemes for compensation, they have set up public inquiries. That is another aspect of the matter which, over time, the Government have failed to institute. I shall not go into the parallels to be drawn between HCV and HIV infection, but many aspects of the two conditions are similar. Over the years, many of us have found the fact that a scheme for HCV sufferers has not been instituted quite incomprehensible. The predicaments of those in the two categories of infection are very similar. Over time, the Government have appeared cold-hearted and miserly in refusing to provide the same level of support.

So it was with considerable optimism that we heard on 29th August John Reid announce the scheme. We all thought that, finally, some sanity was being introduced to the whole area. We thought that an ex gratia payment scheme would be set up and the details worked out over time, it was hoped, in consultation with the Haemophilia Society, which has put forward very constructive proposals for financial assistance or compensation. As the noble Lord, Lord Morris, mentioned, the society drew on the Canadian scheme, which has been extremely successful.

However, all we have heard since 29th August is a deafening silence, which has led to even greater concern. It appears now that the English and Scottish schemes are going to be very similar. There is a feeling, in particular in light of the fact that Lord Ross recommended a payment of £50,000 and yet the Scottish proposal is much lower, that the Government, too, will propose the lower figure. However, the Haemophilia Society makes an extremely good case for the figure of £140,000 as the average payment. Indeed, looking across the Irish Sea to Eire, there the financial assistance being offered averages 300,000 euros; that is a very different order of sum. I hope that, when the Government come to prepare their scheme, that they will enter into a lot of debate and discussion about the proper level of compensation.

The terms of any compensation represent a further major issue. Will the relatives of those who have died from HCV or liver failure as a result of HCV be entitled to compensation? If the Government follow the Scottish scheme, then they will not be so entitled. Ladies such as those who have written to me will then face the prospect of receiving absolutely no financial assistance, which cannot be right.

What of those who have managed to become clear of the virus through treatment, whether by liver transplant or otherwise? What of the distress and suffering that they will have endured during that process? Surely in those circumstances people should be entitled to financial assistance. On 16th September, I asked the Minister a supplementary question related to the compensation scheme; specifically, what is to happen if the condition of a subject deteriorates? A person may be assessed at one level, but what if, over time, he or she becomes more ill? Will the scheme

have built into it the necessary flexibility to allow for reassessment? Will people be entitled to higher levels of compensation in those circumstances?

I turn to the wider issue of co-infection. It would be extremely unjust if no compensation was made available to those patients suffering from both HCV and HIV infections on the grounds that they would have been compensated in part by access to the Macfarlane Trust. They have been subject to a double jeopardy, and financial assistance should be given in those circumstances as well.

When do the Government intend to announce final details? There appears to be funding down the track, and it would be extremely helpful if they said how much further consultation will take place and what the timing of the announcement of the scheme will be. I am particularly concerned that, as time has marched on, the large majority of people with haemophilia who were infected in the late 1970s and early 1980s have reached the more advanced stages of the disease, so they really need that compensation to be available. This money is justified because of their unnecessary suffering and is required for their treatment here and now.

I believe that the Government must act now to account for this awful injustice to so many people. Those individuals have waited long enough, not only to bring the necessary attention to their case—for which they need to thank the noble Lord, Lord Morris, and the Haemophilia Society—but also to receive a proper form of compensation for their unnecessary suffering.

**Earl Howe:** My Lords, it is a pleasure for me to begin by congratulating the noble Lord, Lord Morris of Manchester, on the success of his long campaign to secure financial recognition for recipients of contaminated blood products who, as a consequence, became infected with hepatitis C. If ever there were an example of a tireless champion of the disadvantaged and the disabled, and of someone undaunted by ministerial stonewalling, it is surely the noble Lord. I have to confess to him that before the Government's announcement in August, I did not rate his chances of success on this particular campaign as very high. However, I was wrong, and I salute him.

It is also right to acknowledge the humanity and compassion of the Secretary of State in taking the brave decision to make ex gratia payments to those unfortunate victims of medical accident and, in doing so, to reverse the policy of his predecessors.

I knew I would find myself saying this, but the noble Lord, Lord Morris, has stated his case so eloquently that there is little I feel I can add to it. But now that the Government's decision has been taken, I believe that there are some key principles that should guide them in determining the way in which the ex gratia payments are distributed.

The most important of these is that the scheme needs to be fair and to be perceived as fair. In the first instance, our thoughts turn most naturally to those who, as a result of receiving infected blood products, have to live with hepatitis C and, perhaps, its more severe consequences, for many years. However, I very much share the noble Lord's concern for the widows and dependants of those who have already died of advanced liver disease or liver cancer in consequence of a contaminated transfusion.

We also need to remember that there are many people who, although now clear of infection, have been to hell and back in fighting it off. We all understand that the money to be paid by the Government does not constitute compensation in the legally accepted sense of the term. But if the intention of this scheme is to recognise the suffering of the victims and their families, and the moral responsibility borne by the NHS, then it seems to me that there should be no messing about. Financial recognition should be given to all those adversely affected, not simply people who were fortunate enough to be alive and ill—if fortunate is the word—on the date of the Government's announcement in the summer.

The second principle that should guide the Government is certainty. When the Government in due course announce the details of the ex gratia scheme, everyone entitled to an ex gratia payment should be made aware of exactly what their entitlement comprises. One potentially foggy area highlighted by the noble Lord is co-infection. The Macfarlane Trust exists to help recipients of contaminated blood who later went on to contract HIV. Those who already benefit from that scheme but who are living with hepatitis C alongside HIV need to know whether they are eligible for additional financial assistance. About 500 individuals fall into that category.

In thinking of those people, we should not be in any doubt of the anguish, pain and financial disadvantage that they now suffer by reason of their hepatitis C and its consequences, as distinct from the consequences of their HIV infection. As well as that, we should remember that the progression of hepatitis C is accelerated by HIV, and liver failure is now the leading cause of death in the group. In formulating the scheme, will the Government bear in mind the especially harsh consequences of co-morbidity?

If there is to be a graduated structure of payments, the rationale for it needs to be made clear. I do not intend to draw the Minister on the precise amounts that might be paid to particular groups of individuals, partly because I do not believe that

he would tell me even if I did. However, supposing that there were to be a stepped entitlement dependent on the severity of a person's illness, it is important for everyone to understand why those particular figures have been arrived at.

There are benchmarks that may be helpful in that matter. One is the structure of payments made to HIV-infected patients by the Macfarlane Trust. Another, well known to the noble Lord, Lord Morris, is the vaccine damage payments scheme. There are other benchmarks from case law. My point is that sums of money should not simply be plucked out of the air but should be determined in relation to the scale of the suffering that they are intended to ameliorate.

I understand that the Minister cannot go into detail today, but will he tell me whether the payments under the scheme are being worked out within the framework of a predetermined budget or whether, as I hope, the payments are to be fixed in a way that might most conveniently be described as bottom-up?

Earlier this year, the Chief Medical Officer published a paper called Making Amends. It would be helpful if the Minister could make clear how, if at all, those recommendations relate to the scheme of ex gratia payments that we are now debating. The CMO's consultation paper offered alternatives to tort-based litigation for those who felt that they might have suffered as a result of NHS treatment. A large part of the recommendations relates to injuries caused by someone's fault, which are clearly not relevant to the matters that we have discussed today. With the hepatitis C victims, there is no admission or suggestion of fault.

Another of the CMO's proposals is more relevant, however. It relates to babies who sustain brain damage resulting from their birth. That proposal for compensation expressly excludes the concept of fault. The only requirement is to prove causation. In such cases, the proposals for compensation include a managed care package, a lump-sum payment and annual payments on top of them.

Although the Government have been careful to make it clear that the ex gratia scheme for hepatitis C victims does not constitute a precedent, it cannot be viewed in isolation. I realise that the CMO's paper is only a proposal at present, but it is clearly a carefully considered piece of work. Under what circumstances do the Government believe that a no-fault compensation scheme may have a part to play, and in what way precisely does such a scheme differ from an ex gratia payment scheme such as the one that we have discussed? What criteria are applicable to each? To put it another way, exactly why did the Secretary of State decide to opt for an ex gratia scheme rather than a no-fault compensation scheme such as that envisaged by the CMO?

In general, it would be helpful to hear from the Minister some of the Government's thinking on this scheme and an idea of when Ministers expect to make a further announcement on the details. Above all, I hope that the announcement when it comes will prove, at the very least, satisfactory to all those who have suffered so grievously and to whom the sympathies of the whole House are extended.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Warner):** My Lords, I thank my noble friend for reminding me of my misspent youth in so generous a way. I was taken down memory lane very agreeably by his opening remarks.

My noble friend has done much to keep this matter at the forefront of the Government's mind and is now providing me with an opportunity to give the House an up-to-date statement on the progress that we have made so far. In doing so, I shall endeavour to cover the points raised by my noble friend and other noble Lords.

Let me start by congratulating my noble friend on his absolutely outstanding record of commitment to this cause over many years, as other noble Lords have done. His efforts on behalf of people with haemophilia infected with hepatitis C as a result of treatment with NHS blood and blood products, and his service as the long-standing president of the Haemophilia Society, are widely recognised and valued in all parts of the House and outside, and by the Government.

I should also like to pay tribute to those people who took part in the Haemophilia Society's annual Garland of Lilies Day last week. We extend our sympathy to them on the loss of their loved ones.

The background to this issue is well documented and has been the subject of many debates in both this House and in the other place. Suffice it to say that the inadvertent infection of many thousands of people with hepatitis C as a result of treatment with NHS blood and blood products in the 1970s, 1980s and 1990s remains a tragic event in the UK and in many other countries around the world. These patients were at the time given what was considered by professionals to be the best treatment available. It was a terrible tragedy that medical advances in virology could not keep pace with those being made in transfusion and blood technology—technology which is fundamental in saving lives today.

No one can be but moved by the accounts of personal tragedies that individuals and their families have given to Members of the House and elsewhere. The inadvertent infection with hepatitis C was indiscriminate, affecting both those who regularly required blood products, such as people with haemophilia, as well as patients who received one-off blood transfusions. Fortunately, following the introduction of heat treatment technology in 1985 and donor screening in 1991,

there is now only a minute chance that further infections will occur. But this is of little consolation to those who were infected before these scientific breakthroughs could be fully implemented.

The Government have enormous sympathy for people who have suffered infection via contaminated blood products and recognise the hardships that illness has brought on them and their loved ones. Those who were infected, and campaigners such as my noble friend Lord Morris, have longed called for social justice with regard to this issue and we acknowledge those efforts.

For its part, the Department of Health understands only too well the difficult dilemma where treatment and care can lead to harm where none is intended. Having looked at the history of this issue, my right honourable friend the Secretary of State for Health decided in the summer that the establishment of a financial assistance scheme for those affected by these events was the right thing to do. I am grateful for the generous remarks of noble Lords about my right honourable friend's actions.

When the hepatitis C payment scheme was announced on 29th August few details were available. Nevertheless, the fact that the Government had decided in principle that such a scheme should be set up has received universal approval. I am now pleased to report that significant progress has been made in drawing up the details of the scheme.

Discussions on the specifics of the scheme have been continuing in the department since before the August announcement. First and foremost, we have taken steps to ensure that the scheme will be fully inclusive and fair. Officials have met on a number of occasions with their counterparts in the health departments of the devolved administrations in Scotland, Wales and Northern Ireland to co-operate in the development of a scheme that will cover the whole of the UK.

Although it would be premature for me to comment on those discussions in detail, I can confirm that a system will be put in place to ensure that all eligible UK claimants will benefit no matter where they currently reside, or where they were resident when they contracted the disease. We shall work hard to ensure that those eligible for payment under the terms of the scheme do not miss out because they may have crossed a border since their initial treatment.

Noble Lords will be aware that the Minister for Health in Scotland, as has been said, has already announced the proposals for the Scottish Executive's payment scheme. These proposals are being considered by the administrations, along with other independent recommendations such as those made in the report of the Hepatitis C Working Party to the Haemophilia Society and the report of the Scottish Expert Group chaired by Lord Ross.

My noble friend raised the question of whether the proposed scheme would simply follow that announced by the Scottish Executive earlier this year. The scheme envisaged for Scotland was clearly based on the particular circumstances in Scotland at the time. Following the Secretary of State's announcement in August, it was important that all available information was taken on board, including the reasons behind the Scottish scheme. That is why we have had many discussions with the Scottish Executive to try to produce a UK-wide scheme.

Parallel discussions in England, Scotland and Wales have also included major patient organisations, including the Haemophilia Society. We are grateful to the groups that have participated for raising issues and contributing to the development of the scheme. I am also aware that my honourable friend the Parliamentary Under-Secretary of State for Public Health has met with the chair of the All-Party Parliamentary Group on Haemophilia of which my noble friend Lord Morris is the honorary president.

This debate also gives me the opportunity to pay tribute to the work of that group in promoting the interests of people with haemophilia. We are keen to take on board the comments made by these organisations and are considering them during our deliberations. We continue to correspond with these and other groups to keep key stakeholders up-to-date with developments.

Officials from the health departments have also met and consulted with clinical experts, including leading hepatologists and haematologists on various aspects of the scheme and regularly call upon the expertise of the National Blood Authority. These consultations are an integral part of developing a scheme, but noble Lords will appreciate—I think that the noble Earl, Lord Howe, anticipated this—that I cannot, as yet, make public further details, although I expect my right honourable friend the Secretary of State for Health to make an announcement before too long.

Following the announcement in August, the Department of Health received an enormous number of inquiries from people eager to take forward applications and benefit from the proposed scheme. Officials have moved swiftly to ensure that direct contact could be maintained with inquirers to keep them up to date with developments.

To this end, the department has established a confidential mailing list to keep a record of all those who contacted us. In order to make the mailing list as accessible as possible, telephone, e-mail and postal contact details were provided and those who had not yet got in touch were encouraged to do so, for example via the Haemophilia Society website and newsletters.

The mailing list now comprises scores of names and continues to grow day by day. Registrants will be contacted regularly in the near future as further details of the scheme are released and the application process is finalised. We believe this to be an important initiative as it gives would-be claimants confidence that their details have been noted and that they will be given an opportunity to make a claim once the scheme has been finalised and announced.

As well as opening a constructive dialogue with the Haemophilia Society, we are also listening to other patient groups and individuals and consider any concerns that they raise. We have received correspondence from various sources, including MPs, lawyers writing on behalf of clients, clinicians writing on behalf of their patients and bereaved families as well as people with hepatitis C themselves. All those letters have been replied to and we have put their contact details on to the mailing list that I mentioned.

As well as providing advice, the National Blood Authority is involved in the identification of people who may have received hepatitis C-infected blood transfusions. We are co-operating with the authority in an effort to ensure that people who contact it regarding the scheme are referred on to the department.

My noble friend is aware that there are a number of legal and other difficulties—some have been mentioned this evening by many noble Lords—associated with the introduction of an ex gratia payment scheme. Many of those issues were successfully overcome during the establishment of the MacFarlane and Eileen trusts for people infected with HIV as a result of treatment with infected blood or blood products. We will, as a matter of course, look to those other schemes to learn lessons on how best to implement and operate the scheme that we are discussing. We are also looking at the detailed issues very carefully, and these are not constrained by any arbitrary fund.

My noble friend raised some issues about a public inquiry into the infected blood issue. I have to make it clear in as gentle a way as I can that the Government do not accept that any wrongful practices were employed, and do not consider that a public inquiry is justified. Donor screening for hepatitis C was introduced in the UK in 1991, and the development of that test marked a major advance in microbiological technology that could not have been implemented before that.

My noble friend referred to other countries, but we do not believe that they are comparable to the situation being dealt with in the UK. In Ireland and Canada, for example, compensation schemes came about because the blood authorities were both found to be at fault. Indeed in Canada, criminal prosecutions were filed against those responsible. It is important to stress that, despite our decision to make ex gratia payments, the position with regard to accepting liability has not changed. The payments are made on compassionate grounds and are not compensation. With that in mind, the payments cannot be expected to take account of loss of earnings or compare with punitive damages awarded by the courts in other countries. That said, as part of our deliberations we are considering, as other noble Lords have mentioned, the report of the hepatitis C working party to the Haemophilia Society, which I understand is based on the Canadian model.

Noble Lords will be reassured to hear that we are working closely with government lawyers and other government departments to resolve outstanding issues specific to the scheme and to minimise delay. In particular, I know that concerns about social security disregards have been voiced, and we are working closely with the Department for Work and Pensions and the Treasury to address those.

My noble friend raised the issue of arbitrary dates of death, which is part of the deliberations currently going on with regard to the question of payments to dependants. We wish to try to resolve those problems satisfactorily.

In addition, concerns have been raised by and on behalf of recipients of financial assistance from the MacFarlane and Eileen trusts, who have signed a waiver that may exclude them from making claims under the proposed scheme. Obviously we are urgently looking at the status of that waiver and hope to reach a conclusion that will be satisfactory to any such claimants.

So what will the Government be doing next? Our discussions are continuing apace on all the issues, with special priority being given to finalising the eligibility criteria and payment structure. We are also working on setting up a system to administer payments under the new scheme. As I have indicated, we expect to be in a position to make a further announcement detailing those very soon. In the mean time, we will continue to listen, consider and respond to comments that we receive. In addition, we are putting in hand the necessary work to ensure that the scheme is up and running as soon as possible.

My noble friend mentioned some issues around variant CJD. The answer to his main question is that we do not know whether variant CJD can be transmitted by blood. Therefore, we do not have any diagnostic tests for it in blood. He also made some remarks about the CJD compensation scheme. The Government have set up a variant CJD compensation scheme that will provide for payments to be made in respect of 250 cases of variant CJD up to a maximum of £55 million.

In recognition of the exceptional circumstances, on top of the £55 million trust fund, the Government will pay £50,000 to each victim in the family. The Government have committed enough funds to cover the 250 cases. One hundred and thirty-four victims are receiving money. I hope that I have provided the noble Lord with some background on that issue.

In conclusion, I am sure that noble Lords will agree with me when I stress the importance of setting the scheme up properly from the outset. It is always terribly easy to rush into those areas and to get things wrong. Despite the tragic circumstances of many victims, speed does not necessarily mean that we get it right. Although it may take a little more time than we would like—indeed, much more time than we would like—the benefits of introducing the scheme properly are obvious. It would be a great shame if a "rush job" left us with an inefficient or poorly structured scheme. On that basis, I thank noble Lords for their contributions today and reassure them that we expect to be in a position to respond more fully to their questions shortly, and to make an announcement soon.

#### **Haemophiliacs with Hepatitis C: Financial Assistance Scheme**

16<sup>th</sup> September 2003

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper; and in doing so declare an interest, not a pecuniary one, as president of the Haemophilia Society.

The Question was as follows:

To ask Her Majesty's Government what further consideration they have given to introducing a financial assistance scheme for people with haemophilia and other National Health Service patients infected with hepatitis C by contaminated National Health Service blood products; and what action they are taking in this regard.

**Baroness Andrews:** My Lords, I am pleased to be able to report that my right honourable friend the Secretary of State for Health announced on 29th August that the Government have decided to establish a financial assistance scheme in England for people infected with hepatitis C as a result of being given blood or blood products by the NHS.

**Lord Morris of Manchester:** My Lords, I am most grateful to my noble friend who knows how evocative a moment this is for those who have worked for so many years—not least from both sides of this House—to achieve this major and welcome change of policy.

Can we be assured that the payments scheme, on the detail of which the Haemophilia Society looks forward to working with government, will cover dependants of the 212 haemophilia patients who have died of hepatitis C infection, as well as the 2,800 still living with the virus?

How many of the 2,800 now have advanced liver disease, including cancer and cirrhosis, due to the virus; and what number still await liver transplants as their only remaining hope of survival?

Finally, will the scheme take full account of what other schemes provide, such as those in Canada and Ireland, and of the £100,000 now available under our own Vaccine Damage Payment Scheme?

**Baroness Andrews:** My Lords, I am sure that the whole House would want me to start by congratulating the noble Lord on his outstanding record of promoting this social justice cause for haemophiliacs infected with blood products. Since the early 1980s he has played an outstanding role. He would probably want me to thank Ministers in this House who over the years have shown great sympathy and support for this cause and who will be very pleased that it has been resolved in this manner.

In relation to his questions, I cannot give an assurance on any of the details at the moment because meetings are urgently taking place to discuss the scope and nature of the scheme, the inclusion of dependants, and so forth. I understand that there is to be a meeting between the Department of Health, the Macfarlane Trust and the Haemophilia Society.

On the number of people who have advanced liver disease, we do not hold those figures centrally, but I believe that about 20 per cent of chronically infected people may develop serious liver disease and that about 4 per cent might get liver cancer as a result. But these issues are being addressed in the Hepatitis C Strategy, which is in place.

In relation to other schemes, this scheme is not comparable. It is a unique scheme. It has been introduced on compassionate grounds. It is a financial assistance scheme. As such, that is exactly what it will deliver.

**Lord Clement-Jones:** My Lords, I join the noble Lord, Lord Morris, in congratulating the Government on their change of mind after many years on this subject and paying compensation towards those infected in this way. I also join the Minister in congratulating the noble Lord, Lord Morris, after his campaign, together with the Haemophilia Society, on finally securing this change of mind by the Government.

When the Government consider the details of the scheme, will they take into account the way in which the Macfarlane Trust operates for those haemophiliacs infected with HIV after being given blood products, in so far as they are able to claim for higher compensation if their condition deteriorates?

**Baroness Andrews:** My Lords, we are grateful for the noble Lord's support. I reiterate that this is a scheme of financial assistance, not compensation, because there was no liability. Given the knowledge and techniques available to the National Blood Service at the time, everything was done as it should have been.

On the noble Lord's question about the Haemophilia Society, the Macfarlane Trust and those who receive support from it, that will be on the table and discussed, along with many other issues.

**Lord Campbell of Croy:** My Lords, while welcoming the decision on ex gratia payments, can the Minister confirm that many people are still living who contracted hepatitis C from contaminated blood in the health service? How many of them are waiting for liver transplants, which are essential for their survival?

**Baroness Andrews:** My Lords, I am afraid that I do not have that information for the noble Lord. We do not collect statistics centrally, but I shall certainly return to the department to try to obtain that information—or at least an educated guess—for him.

**Lord Ackner:** My Lords, in deciding on the scale of compensation, will the Minister have regard to the provisions of the Criminal Injuries Compensation Act 1995? In particular, will she bear in mind that millions of pounds—last year it was £232 million—are paid out to victims of crime for whom the Government are in no way vicariously responsible, whereas here we are concerned with persons whom the health service has infected? Is she aware that under that compensation scheme, a figure is paid for the actual injury, and that to that is added loss of earnings or the ability to earn, as well as special expenses such as the cost of medical care that cannot be covered by the NHS, costs of adapting a house, and other such items?

**Baroness Andrews:** My Lords, I sympathise with what the noble and learned Lord says, but there is no comparison between what the Government are doing to provide ex gratia payments on compassionate grounds for financial assistance and the criminal injuries compensation scheme, which implies liability. As I said, there was no liability when this unfortunate event occurred. There was no test until 1991 for hepatitis C so, like every other country, in the early 1970s we could not know what was happening. The noble and learned Lord is comparing like with unlike, so I cannot give him the satisfaction that he seeks.

#### Hepatitis C

26<sup>th</sup> February 2003

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper. In doing so, I declare an interest—not a financial one—as president of the Haemophilia Society.

The Question was as follows:

To ask Her Majesty's Government what new help is under consideration for people with haemophilia who were infected with hepatitis C by contaminated National Health Service blood products and the dependants of those who have since died of their infection.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):** My Lords, we recently announced an extra £88 million over the next three years to provide synthetic clotting factors for haemophilia patients. Our aim is that by March 2006 the vast majority of haemophilia patients should be receiving those products.

**Lord Morris of Manchester:** My Lords, I am grateful to my noble friend both for that reply and for the change of policy announced in his written reply to me on 12th February about making the safer recombinant treatment available to haemophilia patients nationwide. When will the promised further meeting take place with the Haemophilia Society to discuss its compensation proposals for people infected with hepatitis C by contaminated NHS blood products?

Again, is my noble friend aware of the Scottish Executive's proposals for financial recompense and can we be absolutely assured that infected patients will not be treated differently according to where they live in the United Kingdom?

**Lord Hunt of Kings Heath:** My Lords, I thank my noble friend for his remarks and pay tribute to him and to the Haemophilia Society for their efforts in this direction. The Government are still considering the details of the report submitted by the Haemophilia Society. We will respond to the society and my noble friend as soon as our consideration of the report is complete.

A report from a Scottish expert group is being considered by the Scottish Executive. I understand that no decisions have been made. Of course, that does not affect the position in England; it is solely a matter for the Scottish Executive.

**Lord Campbell of Croy:** My Lords, although the infection was accidental and arose from treatment intended to be beneficial, do the Government accept that they have a duty to assist all those who have been infected in coping with the consequences?

**Lord Hunt of Kings Heath:** My Lords, I agree that the National Health Service should do everything it can to ensure that the services it provides are as effective as possible. If the noble Lord was raising the question of compensation—I think he may have been—he will know that as soon as the technology to make blood products free from hepatitis C was available, it was introduced by the National Health Service. The Government have given the matter long and hard consideration. We reached the same decision as did the previous government—that there was and is no legal liability on which we could justify paying compensation.

**Lord Walton of Detchant:** My Lords, although the Minister is absolutely right to say that there is no legal liability to compensate those infected by the agent through no fault of their own, and although it is true that the whole spirit of no-fault compensation has been anathema to successive governments, is there not a strong moral obligation on the Government to compensate those individuals infected with hepatitis C through receiving that treatment?

**Lord Hunt of Kings Heath:** My Lords, I cannot pretend that it was an easy decision for the Government to make. We gave the matter careful consideration and, in the end, felt that the decision taken by the previous Conservative government was right.

**Lord Clement-Jones:** My Lords, the NHS has made the far-sighted decision to fund synthetic blood treatment for haemophiliacs—we all welcome that. Why cannot the Government, for less money than is being made available for synthetic products for those who could prospectively be infected by hepatitis C, do the same for those who have been infected by blood products in the past?

**Lord Hunt of Kings Heath:** My Lords, I cannot add anything to my previous answers. We have given the matter careful consideration. The fact is that, as soon as the technology became available to make blood products free from hepatitis C, the NHS introduced it. There is no legal liability to justify compensation for those who were so unfortunately affected in that way.

**Baroness Finlay of Llandaff:** My Lords, does the Minister know how many patients infected with hepatitis C who have inherited bleeding disorders are able to access state-of-the-art treatment with pegylated interferon and ribavirin and with specialised hepatology follow-up?

**Lord Hunt of Kings Heath:** My Lords, we have referred the matter to the National Institute for Clinical Excellence. It is considering pegylated interferon; it expects to issue guidance to the NHS in November 2003.

**Baroness Masham of Ilton:** My Lords, I declare an interest as the vice-president of the Haemophilia Society. Why are patients in Wales and Scotland receiving recombinant, which is a safer form of blood product, but not patients in England? How long will it take for all English haemophiliacs to receive it?

**Lord Hunt of Kings Heath:** My Lords, as I said in my Answer, we expect that the scheme will have been completely introduced by 2006. The position in Scotland and Wales is an issue relevant to the administrations there.

The number of haemophilia patients in the rest of the UK is much smaller than that in England. That is also a factor in determining the timescale for introducing the scheme completely. I can also reassure the noble Baroness that the Government will work with the Haemophilia Society to put in place a strategy to implement the scheme effectively.

**Lord Ackner:** My Lords, is the Minister aware that, in 2001, we spent £206 million in compensating those injured by criminals? That is 341 million euros. The combined amount spent by the whole EU, excluding ourselves, is less than what we paid. They paid out 290 million euros. Does the noble Lord agree that the demands on the generosity of the Government with regard to haemophiliacs should be greater? They were injured by the NHS, as opposed to being victims of criminal behaviour, for which the Government are in no way vicariously responsible. Will the noble Lord explain why there is one law for those injured by others and another for those injured by the NHS?

**Lord Hunt of Kings Heath:** My Lords, the cases are different. The criminal injuries compensation scheme makes payments to victims of violent crime. That is a different set of circumstances from the one we are discussing. I have already explained why the Government made the decision that we did.

I do not pretend that the question is an easy one. To noble Lords opposite, I say that their government also had to make a difficult decision, and I believe that they made the right one. It is not easy. We all recognise the problems of those affected, but I do not think that it is justifiable to move from the principle that I enunciated.

## Hepatitis C

13<sup>th</sup> January 2003

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper. In doing so, I declare an interest—not a financial one—as president of the Haemophilia Society.

The Question was as follows:

To ask Her Majesty's Government what new help they are considering for people infected with hepatitis C by contaminated National Health Service blood products, and for the dependants of those who have since died as a result of their infection.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):** My Lords, we have enormous sympathy with those affected by this tragedy. Sadly, it was not possible at the time to make blood products free from hepatitis C. We do, however, recognise the public health importance of hepatitis C and have published a strategy to improve the effectiveness of prevention, testing and treating services for people with this virus. An action plan to implement the strategy will be produced in the next few months.

**Lord Morris of Manchester:** My Lords, I thank my noble friend. Is he aware that last month, for the third time, haemophilia patients were notified that NHS blood products they were prescribed trace back to a donor with variant CJD; and that the Department of Health, with no tests for the disease, cannot say whether they have contracted it?

Over 1,000 haemophilia patients have now died from the HIV and hepatitis C viruses transmitted by contaminated NHS blood products—a huge toll for a small and already stricken patient community of only 5,000. Is it not then cruelly unjust to deny those who survive the safer recombinant treatment that would remove their fear of further infection?

Again, is my noble friend aware of the Market Research Bureau's finding that the UK now has the lowest availability of recombinant for haemophilia patients in the developed world?

**Lord Hunt of Kings Heath:** My Lords, I pay tribute to my noble friend for his presidency of the society. This has been a tragic event that has occurred in this country. The previous government decided that the general rule should apply in those cases: that there could not be an exception to the rule that compensation or financial help is given only when the NHS or individuals working in it are at fault. The current Government reviewed this decision by the previous government some years ago and decided that they could not move from that position.

So far as concerns recombinant synthetic factors 8 and 9, Ministers are currently considering the case for the provision of recombinant clotting factors and hope to be able to make a decision shortly.

**Lord Campbell of Croy:** My Lords, what approximately is the number of people now infected in this way, and the number of their dependants as at present?

**Lord Hunt of Kings Heath:** My Lords, the figures that I have indicate that about 8,000 people are still living who are infected with hepatitis C through blood products and blood transfusion.

**Lord Addington:** My Lords, will the Government please explain to the House the difference in the circumstances of the relatives of people who have died as a result of contracting HIV through no cause of their own, and those of someone who has died of cancer of the liver caused by hepatitis C?

**Lord Hunt of Kings Heath:** My Lords, these are very difficult judgments. I do not think that anyone who has gone into this matter—in the previous government or the current Government—has found making a decision in this area at all easy. At the end of the day, after careful review, we came to the conclusion that we could not make an exception to the compensation rule.

**Lord Rix:** My Lords, does that mean that there is a lack of conviction about the cost or about the treatment?

**Lord Hunt of Kings Heath:** My Lords, I do not believe that those are the issues that are paramount in considering this matter. There has long been a general rule that compensation is given by the National Health Service only when the service itself or individuals working in it are at fault. In this case, there has been no fault.

**Baroness Gardner of Parkes:** My Lords, what number of patients in general are suffering from hepatitis C; and is adequate treatment being offered to them, whether or not they are haemophiliacs?

**Lord Hunt of Kings Heath:** My Lords, the current information I have is that the prevalence of chronic hepatitis C infection may be around 0.4 per cent of the general population: that is about 200,000 people in England. Therapies are available for treatment, most notably the combination therapy interferon alpha with Ribavirin. There is also a combination treatment which includes pegylated interferon, which is currently being reviewed by NICE. There is also currently a clinical trial assessing treatment for mild disease. That is due to report later in the year.

**Lord Ackner:** My Lords, I am sorry to take up the time of the House, but I do not follow why the National Health Service has the principle of no compensation unless there is fault; whereas, every year, millions of pounds are handed out to victims of criminal activity—to those who are injured by criminals. In that situation, there is no fault on the part of the Government; in fact, many would say that there is no moral obligation. In this case, there is a strong moral obligation because the NHS has caused the trouble. Will the Minister please explain whether there is some special rule for the NHS; and, if so, what is its justification?

**Lord Hunt of Kings Heath:** My Lords, the noble and learned Lord has raised this matter on a number of occasions in your Lordships' House. I believe that the cases are very different and they have been recognised as such both by this Government and by the previous government. The Criminal Injuries Compensation Scheme makes payments to victims of violent crime. The scheme recognises society's sympathy with the victims of such deliberate and malicious acts of violence. I believe that those circumstances are very different from the circumstances in which the NHS provides treatment to patients.

**Lord Davies of Coity:** My Lords, following on from the previous question, I understood my noble friend to refer to the issue of "fault". Given that, as the Question says, people have been infected,

"by contaminated National Health Service blood products",  
will the Minister express more clearly how the National Health Service can say that there is no fault when its product has caused the complaint?

**Lord Hunt of Kings Heath:** My Lords, it was possible to eliminate hepatitis C from blood products only in 1985, when heat treatment was introduced. The cases that we are discussing, in which people were infected through blood products, relate to people who were infected before that date.

#### Hepatitis C

21 November 2002

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper. In doing so I declare an interest—not a financial one—as president of the Haemophilia Society.

The Question was as follows:

To ask Her Majesty's Government what implications for National Health Service patients identically affected in other parts of the United Kingdom follow from the findings of the expert group appointed by the Scottish Executive to consider financial and other practical support for patients infected with hepatitis C by contaminated National Health Service blood, blood products or tissue.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):** My Lords, the expert group's report was commissioned by the Scottish Executive, and its recommendations on hepatitis C relate only to people who contracted the virus from blood or blood products from the NHS in Scotland. It does not, therefore, have implications for patients in other parts of the United Kingdom.

**Lord Morris of Manchester:** My Lords, is it not much to the honour of the Scottish Executive that it had the case for compensating those infected and bereaved in this worst-ever treatment disaster in the history of the NHS independently examined by an eminent Scottish judge, not as in Whitehall by an in-house inquiry behind closed doors at the Department of Health?

If it is now seen as morally right to compensate in Scotland for hepatitis C infection by contaminated NHS blood products, should not the same moral imperative apply elsewhere in Britain? Is not the Haemophilia Society eminently justified in insisting that to deny parity of treatment in this case would diminish the NHS to a two-tier, two-class and two-faced system of healthcare for the British people?

**Lord Hunt of Kings Heath:** My Lords, I pay tribute to my noble friend for his distinguished presidency of the Haemophilia Society and to the society itself for the vigour with which it pursues its case. The fact is that the matter was considered by this Government and by the previous government. In general, compensation is given only to those who suffer negligent damage from NHS treatment. On that basis, the decision was made that no compensation would be given.

The position in Scotland is a matter for the Scottish Executive. I am, of course, aware of the recommendations of the expert group set up by the Scottish Executive. My understanding is that the Scottish Executive, in welcoming the preliminary report, is now considering what the outcome should be.

**Lord Campbell of Croy:** My Lords, despite what the noble Lord has just said, can the Government give a clear assurance that, if contamination has occurred within the National Health Service, adequate compensation will be given to the individuals who have been affected?

**Lord Hunt of Kings Heath:** My Lords, I can only repeat my words to my noble friend Lord Morris of Manchester. One can only regret deeply the fact that so many people with haemophilia were infected with hepatitis C through blood products. As soon as the technology to make blood products free from hepatitis C became available, the NHS introduced it. On that basis, there is no legal liability to justify compensation for people with haemophilia and hepatitis C.

**Lord Clement-Jones:** My Lords, even though there are separate organisations north and south of the Border, it seems extraordinary that the Minister should say that different moral considerations apply, depending on which side of the Border one happens to be. Malcolm Chisholm, the Health Minister, has been extremely sympathetic to Lord Ross's report, whatever the final settlement is to be.

Is the Minister really saying that the representations of the Haemophilia Society and, in particular, the results of the work of the expert working group set up by the society under Matthias Kelly QC will not be sympathetically received in the circumstances?

**Lord Hunt of Kings Heath:** My Lords, Mr Chisholm welcomed the expert group's preliminary report and said that there were complex medical, legal and financial considerations to take into account. The Scottish Executive will need to consider its further position. There is little point in having devolution—certainly for NHS issues—unless the Scottish Executive and Parliament can come to their own view on such matters, as this Government do.

All that I can do is repeat my great sympathy for those who were affected. The Government have reviewed the matter. The previous government reviewed the matter some eight years ago and came to the same conclusion.

**Lord Walton of Detchant:** My Lords, the Minister gave an answer that was, in every way, factually correct. There is no legal responsibility on the NHS in England and Wales because no negligence was proved. Is there not, nevertheless, a strong moral responsibility to offer compensation to those infected through no fault of their own when blood products used for the treatment of haemophilia were infected with hepatitis C? No one could have predicted that, but the moral responsibility is very strong.

**Lord Hunt of Kings Heath:** My Lords, noble Lords will know that the Government gave careful consideration to the matter and to the point raised by the noble Lord, as did the previous Government in 1994-95. Undoubtedly, meetings took place with the Haemophilia Society, and it argued its case strongly. I cannot pretend that the decision that the Government made was easy, but we decided that we could not make an exception to the general rule in this case.

**Lord Roberts of Conwy:** My Lords, in an earlier reply, the noble Lord referred to "negligent damage". Surely, there was damage from the contamination. As for negligence, whose can it be, other than that of the NHS?

**Lord Hunt of Kings Heath:** My Lords, as soon as the technology became available to make blood products free from hepatitis C, the NHS introduced it. There was, therefore, no legal liability to justify compensation for people with haemophilia and hepatitis C. The conclusion that this Government reached is exactly the same as that reached by the previous Conservative government—on the same issue and on the same facts—in the mid-1990s.

**Lord Acknor:** My Lords, how does the noble Lord differentiate between this case and the extensive compensation provided for victims of crime? There is no obligation on the Government to provide a penny piece for victims of crime, but, in the past, it was provided on the same basis as the ordinary civil liability. Subsequently, it went on to a tariff system.

Many millions of pounds are provided for victims of crime. Why is there a differentiation between them and the haemophiliacs whom we are discussing?

**Lord Hunt of Kings Heath:** My Lords, we cannot make a straight comparison. The principle that I enunciated has applied to the NHS for many years. It was shared by this Government and the previous government.

Hepatitis C

12 Mar 2002

**Lord Morris of Manchester** rose to ask Her Majesty's Government what new help they are considering for people with haemophilia who were infected with hepatitis C by contaminated National Health Service blood products and for the dependants of those who have since died.

The noble Lord said: My Lords, the purpose of this debate—I speak as president of the Haemophilia Society—is to focus parliamentary and public attention on the now burning sense of injustice felt by a small and stricken community.

Ninety-five per cent of people with haemophilia treated before 1985—some 4,800 people—were infected with hepatitis C—HCV—by unclean NHS blood products. One in four of them was also infected with HIV. Over 800 have now died of AIDS-related illnesses from HIV infection and 212 have died from liver disease linked to HCV.

Yet, already twice stricken, the haemophilia community has now been dealt a cruel further blow. They are told by the Department of Health that blood products on which many rely crucially for their survival came from plasma donated by people who have since died of vCJD.

That briefly is the factual basis of what doctors of the highest distinction—including my noble friend Lord Winston, who is vice president of the Haemophilia Society—have described as the worst treatment disaster in the history of the National Health Service.

Its magnitude explains why the Haemophilia Society has felt moved to protest today about the absence from this debate of my noble friend Lord Hunt of Kings Heath as the departmental Minister appointed to speak in this House for the Department of Health. That my noble friend Lord Filkin is on duty this evening is most welcome to me personally. But I would be remiss not to emphasise how dismayed the haemophilia community are, not least those who are now terminally ill—and the dependants of those who have died—that this is the third debate on the disaster in your Lordships' House when its only health Minister has not been present to participate. They are dismayed too about the blatant discrimination they continue to suffer and the delays, week after week after week, in answering parliamentary questions about the hardship it imposes.

HIV-infected people rightly won financial recompense from the Macfarlane Trust set up by the then government in 1987 as an,

"official acceptance of moral responsibility".

Fifteen years on those infected with HCV at the same time—and by the same route—still await parity of treatment. There is exactly the same moral responsibility for loss and hardship in both cases.

Like HIV infection, HCV can involve heavy financial loss. A survey conducted by the Haemophilia Society, published today, spells out in graphic terms the severity of that loss and the urgency of the need for a positive ministerial response to the practical measures the society proposes on behalf of the 11,000 haemophilia patient community and their families.

Nearly half of those infected with HCV have had to give up work or cut their working week on health grounds; 40 per cent are unable to obtain life insurance; 14 per cent find it impossible to secure mortgages; and 73 per cent can show that their families, as well as they themselves, are adversely affected financially, practically and emotionally by the grossly stigmatising effects of the infection. The survey's findings make ludicrous the argument that there is no stigma in having HCV.

Nor is it tenable for the Department of Health to go on arguing that financial recompense is only ever paid when negligence can be proved. As Karin Pappenheim has pointed out for the Haemophilia Society, if that argument had held in 1987 there would have been no financial recompense for HIV infection; nor, going further back, would the vaccine damage payments scheme ever have been enacted.

Equally flawed was the department's response to the Haemophilia Society's call for a public inquiry into the infection en masse of the haemophilia community. Its response was to say that there had already been an inquiry. But it was an in-house inquiry by the department itself—held in secret—which responsible journalists describe as,

"a whitewash perpetrated behind closed doors".

The "inquiry" reported in 1998, again peddling the fallacy that HCV, unlike HIV, does not involve social stigma, and simplifying the last government's reasons for compensating only HIV infection to the point of crude inaccuracy.

The truth about the in-house inquiry is now exposed in a letter on the disaster sent to me by the noble Lord, Lord Owen. A health Minister at the time when many of the infections occurred, the noble Lord discloses that moneys allocated—and announced to Parliament—for making NHS blood products safer by ceasing to import blood from high-risk donors abroad were not used for their agreed purpose. Self-sufficiency was not achieved as planned but this was not reported to Parliament, although failure to achieve it meant continued reliance on less safe imports. One is entitled to ask how many people with haemophilia could have been saved from life-threatening viral infection had the policy announced in Parliament been duly implemented.

In a letter sent to me on 12th November last, the noble Lord, Lord Hunt, admitted that failure to inform Parliament of this important change of policy in regard to self-sufficiency was never considered by his department's in-house inquiry. Surely that admission alone justifies the call for an independent further inquiry. In the same letter the Minister stated:

"The department's officials are looking into points raised by Lord Owen, and I will write to you again when examination of all the relevant documents has been completed".

Four months on, I am still awaiting his further letter.

All of this deepens the disquiet felt by the haemophilia community about the grossly unjust treatment of those infected with HCV, as does the Government's reaction to Mr Justice Burton's landmark High Court ruling against the National Blood Authority last March. His core finding in awarding significant compensation was that suppliers of blood to NHS patients have a legal duty to supply clean blood. Yet 4,800 haemophilia patients were contaminated by unclean blood and, while the judgment applies directly only to offences after the Consumer Protection Act came into effect in March 1988, its unmistakable logic is that it is right in principle to compensate NHS patients infected by unclean blood.

For that logic not to be applied now to people with haemophilia infected by unclean NHS blood is wrong in principle, cruelly discriminatory and morally perverse. The issue is ultimately one of moral right; and in none of the parliamentary campaigns in which I have been involved in 38 years in Parliament—even thalidomide and those for statutory recognition of dyslexia and autism—have I felt so strongly that campaigning ought not to have been necessary.

Nor should it be necessary any longer to campaign for people with the same disability to have the safest available medical treatment whether they live in Scotland and Wales or in England. As of now, postcode, not clinical need, determines whether haemophilia patients are prescribed safer, but more expensive recombinant clotting factors.

It is deeply disquieting also that even the current policy of entitling children with haemophilia to the safer treatment is sometimes ignored in parts of England. The Department of Health has told haemophilia patients that any danger of infection from plasma from donors who have since died of variant CJD is "theoretical". To which patients reply that "theoretical" dangers ought more properly be put to the test by those who declare them to be theoretical than by a community already twice stricken by life-threatening blood-borne infections.

They ask now simply, "When will right be done?". Only 43 per cent of patients over 20 are receiving recombinant. Fifty-seven per cent are still forced to use blood products and many have resorted to treatment strikes.

I return in conclusion to the issue of financial recompense and the logic of Mr Justice Burton's historic ruling. To go on viewing special help for life-threatening infection, post-Burton, from the narrow perspective of medical negligence is contemptuous of the principle he enunciated.

The Chief Medical Officer is now reviewing existing systems for compensating patients harmed by NHS treatment. And, as Professor Ian Kennedy, who chaired the Bristol Heart Inquiry, has stated, redress for haemophilia patients requires a new initiative outside those systems. He writes to the society:

"It is for this reason that I have urged the Chief Medical Officer's Working Party to contemplate more wide-ranging changes to respond more effectively to those needing financial and other assistance arising from medical mishaps. The community you represent is just such a group".

He goes on to say that the needs of HCV-infected haemophilia patients are,  
"as clear a case of deserving help as any for a compensation scheme based on need, regardless of blame, and funded through general taxation".

Since my last debate, at least two more European countries have set up special schemes for compensating HCV-infected patients. Sweden and Spain have now joined those already providing just treatment and the Haemophilia Society, in developing proposals which could be implemented here, has based them on the experience of those who have led the way all across Europe. I hope very much that my noble friend Lord Filkin will agree that Ministers will now meet the society—and soon—to hear its detailed proposals.

That justice delayed is justice denied was never more strongly felt than it is today in the small community for whom I speak this evening. They want this debate to hasten the end of an injustice that leaves so many of them doubly disabled and in double despair. But if their striving for equity has to go on, let no one doubt that go on it must until justice is done.

**Lord Astor of Haver:** My Lords, before the noble Lord sits down, he mentioned a letter he received from the noble Lord, Lord Owen. Would it be possible for myself and other speakers tonight to have sight of that letter?

**Lord Morris of Manchester:** My Lords, I shall be pleased to make the letter of the noble Lord, Lord Owen, available to the noble Lord, Lord Astor, and also to my noble friend Lord Filkin.

**Baroness Gardner of Parkes:** My Lords, I have given notice that I wish to speak in the gap. As is the tradition, I shall be brief. I arrived late today and when I rang to put my name down for the debate I found that I had just missed the deadline. When I saw that one of the speakers had dropped out of the debate I realised that it was a good opportunity for me to say a few words.

There is very little I can add to what has been said by the noble Lord, Lord Morris; he has covered the issue very thoroughly. One point that he did not raise is that if you have hepatitis and haemophilia, there is no way that you can obtain life insurance. This is highly relevant and is particularly related to the title of his unstarred Question, which refers to the dependants of those who have died.

Haemophilia is extremely distressing, not only to those who suffer from it but to their families. Hepatitis C is also a terrible burden. I support the view of the noble Lord, Lord Morris, that recombinant Factor H should be available for everyone. That is particularly desirable if there is a risk of BSE—which becomes new variant CJD in humans—being transmitted through blood transfusions and blood products. At the moment, no one seems to know what is the position in that regard, but the recombinant factor, which is totally synthetic, would mean that there would be no risk whatever of being infected. That is a very important point.

I shall not take up any more of your Lordships' time. I merely wish to indicate my strong support for the unstarred Question tabled by the noble Lord, Lord Morris.

**Lord Addington:** My Lords, the noble Lord, Lord Morris, has been a doughty warrior for those who suffer from haemophilia. This subject has been discussed before and my noble friend Lord Clement-Jones, who is unable to be here due to a severe but not life-threatening domestic crisis, and I have both spoken on it a number of times.

People with haemophilia have a potentially life-threatening disability which restricts their life. Their history is basically tied up with the fact that suddenly they were led to believe that there was an answer to haemophilia which would enable them to lead normal lives. That answer—clotting agents—turned out to be, effectively, a death sentence or at least placed a great restriction on their lives. Two groups of infection arose—one of which has been dealt with and one of which has not. That is roughly what happened. We then get into the morass of why one group of sufferers is treated differently from the other.

There are definitions of what is "legal responsibility" and so on, but I am sure that a good lawyer could dance circles around them. However, we are not in the job of interpreting the law, we are in the job of making it. We try to give guidance to lawyers as to what they should do.

If the Government provided treatment for a group of people who needed it desperately and offered them the chance of a whole life as opposed to a part life and a life of restriction, and that treatment damaged people in that group in two different ways, there is something fundamentally wrong if only one part of that group receives compensation.

The noble Lord, Lord Morris, has brought forward more information today—I know that he will ensure that we all have copies of the letter of the noble Lord, Lord Owen—but it merely increases the significance of certain actions. However, one fact is absolutely clear: lives have been affected and lives have been foreshortened.

There is a further irony in that new drug treatments mean that someone with HIV stands a better chance of surviving, in better shape, than someone with hepatitis C.

A series of issues come together to make this case more solid every time we discuss it. The Government sit back and adopt a legal defence that states that at a certain time they felt that one form of infection was caused through negligence while they could not possibly consider the other form of infection. The notes suggest that artificial factors should have been used at certain points, but, whatever happens, there is no easy answer as to what should be the cut-off point. If there is, the Government should do something about it. I would never dream of suggesting what level of compensation should be paid. Indeed, given the passage of time, I would suggest that different calculations are probably necessary for the different situations.

But a recognition that the Government have disadvantaged one group against another—perhaps, "a subsection of one main group" is a better way of putting it—and then not treated those subsections in the same way lies at the heart of the issue. We have two groups of people who have acquired different life-threatening diseases through the same treatment. It is not their fault; it is the fault of the treatment they were given. They were told that the treatment would make them better and deal with the underlying condition. Given that information, they would have been insane to refuse treatment. Then, having been damaged, one of the groups does not receive support. There is something wrong about that.

The Government can dig themselves into a certain legal position. However, unless they are prepared to address the fact that there is something very wrong at a basic level, this problem will not go away. Unless they give a better answer—unless they say, "Yes, we will deal with the underlying problem, not put up legal defences"—they will be hearing a great deal more about the issue for a great deal longer.

**Lord Astor of Haver:** My Lords, I begin by paying tribute to the noble Lord, Lord Morris of Manchester, for once again bringing before the House the important subject of those people with haemophilia who were infected with hepatitis C by contaminated NHS blood products. The Haemophilia Society is fortunate to have the noble Lord as its president. Very few national charities or patient representative groups can have such a committed president working so tirelessly and effectively for their cause.

I pay tribute also to the Haemophilia Society for its excellent campaigning and the support work that it does, not only for people with haemophilia, but also for their families and the dependants of those who have died.

I also mention the work of the Haemophilia Alliance, which comprises the Haemophilia Society and the UK Haemophilia Centre Doctors Organisation. They are drawing up the service specification of care for people with haemophilia and related bleeding disorders.

The noble Lord, Lord Morris, made the point that, for the third time in a year, the Government have failed to put up a health Minister for this debate. I have the greatest respect for the noble Lord, Lord Filkin, who always answers my questions effectively. However, I am disappointed that the noble Lord, Lord Hunt, is not here in person to demonstrate the Government's real concern for this group of people who, unfortunately and tragically, received infected blood products before the hepatitis C infection could be removed.

In addition to the inadequate support services for managing HCV, and the poor management and care after diagnosis, the noble Lord, Lord Morris, set out some of the problems that such people face financially and emotionally. It is quite wrong that they should experience this social stigma or discrimination, wherever it occurs. We on these Benches feel a great deal of sympathy for them.

In preparing for this debate, I went back to the debate introduced last year by the noble Lord, Lord Morris, to look at the issues that we raised at that time. On the subject of comprehensive care centres, which provide specialised care and support for patients and their families, some progress does seem to have been made. Postcode prescribing is less the case this year, but there are still some glaring gaps.

In the debate last year, I raised my concern that there was not one CCC in the South West. For haemophiliacs living in Cornwall or Devon the nearest centre was in Basingstoke, in Hampshire, 237 miles from Penzance. That situation has not changed, as was highlighted by my honourable friend the Member for South West Devon in a Westminster Hall debate last November. I understand that the regional commission group is considering the provision of a CCC in the West Country. I should be grateful if the Minister, in replying, could give some hope to the haemophiliacs living there, given the very real problems that they face.

Last year, I asked about the Hepatitis C Expert Steering Committee which the Government were setting up to produce a consultation document. This was to consider the wide range of specialist services which treat, support and care for people with hepatitis C. This consultation document, *Children in Need and Blood-Borne Viruses: HIV and Hepatitis* was published last month. Unfortunately, it was a missed opportunity. It addressed children only, not adults. All children are treated with recombinant up to the age of 16, so the issue of adults being infected with blood-borne viruses was not addressed.

I also raised the issue of there being no nation-wide system to identify and monitor people with haemophilia infected with HCV and asked the Government what plans they had to ensure that such a system was created. Unfortunately, no progress has been made on central identification. Will the Minister tell the House what intentions the Government have on the issue?

I raised the important point that the majority of health authorities either did not provide treatment for HCV, or did so only on a limited and inadequate scale. Once again, no progress has been made, although we hold out some hope that, following the reforms to NICE, this wrong will be righted.

In last year's debate, the noble Lord, Lord Clement-Jones—who I am sorry to see was unable to take part in the debate—pointed out the fears that the Government were putting haemophiliacs in England at risk from variant CJD. That situation has also not changed. Indeed, as the noble Lord, Lord Morris, pointed out, only 43 per cent of patients are receiving the safer, but more expensive, alternative to the blood plasma which they have been warned may contain vCJD. Indeed, many haemophiliacs are refusing blood transfusions because of fear of contracting vCJD. As the noble Lord, Lord Morris, said, some have resorted to treatment strikes, even though they could die without regular transfusions. In England, unless they are new patients, or under 16, haemophiliacs must use blood products derived from human blood, with all the risks that this might entail; whereas sufferers in Scotland, Wales and Northern Ireland are given the safe, genetically-produced recombinant Factor 8. That is indeed postcode care for haemophiliacs.

Last year, I cited the absurd example from the North West. The policy adopted by the NHS commissioners in Wales means that all haemophiliacs living in North Wales are entitled to receive recombinant Factor 8 irrespective of age, postal code or viral status, and attend the Manchester or Liverpool centres. However, many people living in Manchester, Liverpool and the surrounding areas do not have the same rights and benefits. That situation has not changed.

If someone is infected with contaminated blood products provided by the NHS, surely that person is entitled to the best support and treatment. The Haemophilia Society is in no doubt as to the superior quality of recombinant blood agents.

In a Written Answer last year, the noble Lord, Lord Hunt, said that his department was carefully considering the case for extending provision of re-clotting factors to all haemophiliac patients in England. Has any progress been made on this issue? What reason is there for further denying to adult haemophilia sufferers in England the safer recombinant clotting factors? Was the decision to withhold this treatment taken on financial grounds?

In the Westminster Hall debate on 20th November, the Minister said that there was a world shortage of recombinant Factors 8 and 9. However, according to an article in *Haemophilia World*, supply to the UK is available in sufficient quantities. Moreover, the noble Lord, Lord Hunt, admitted, in an exchange with the noble Lord, Lord Turnbull, that that shortage has now eased. According to the Government, the additional cost of making recombinant treatment available to all haemophiliacs in England would be in the region of £50 million a year. Can the Minister enlighten the House on whether recombinant will be provided to all, regardless of where they live or their age?

Last year, I raised the issue of the lack of welfare support for many haemophilia sufferers. Again, nothing has changed. It would be helpful to have some reassurance from the Minister that the problem will be looked at.

The need for more funding for research was also raised. Progress is being made slowly, but it is too slow for those infected. Perhaps the Minister can touch briefly on funding for research when he winds up.

Finally, in a Westminster Hall debate on 14th November last year, the health Minister John Hutton announced the Government's intention to reform the system for dealing with clinical negligence claims, with a White Paper due "early next year". As it is now "early next year", can the Minister tell the House when it might be forthcoming?

**Lord Filkin:** My Lords, I start my response to this important debate by marking the contribution of the noble Lord, Lord Morris, on the issue over many years. By my count, over the past four years there have been four significant debates in the House on the subject and 45 PQs—although my arithmetic could be faulty. The fact that the Government do not always agree with the noble Lord should not detract from the respect that we hold for his campaigning for this group of people.

I was slightly saddened by the noble Lord's remarks about my noble friend Lord Hunt. I know—and I know that the noble Lord, Lord Morris, knows—that my noble friend is one of the most committed and principled Ministers of health that

anyone could hope to find. From several conversations that I have had with him, I know that he is concerned about the issue and agonises about it. I assure the House that his absence today is certainly not caused by any lack of interest or concern. Any implication that might have been inadvertently carried is misplaced.

All noble Lords who have spoken have raised some important issues. Haemophilia is a lifelong, painful and debilitating condition, but modern treatment can be very effective. It is not effective for everyone, but many patients look forward to an excellent quality of life. Medical science has transformed the situation over the past 30 years.

One of those changes came in the 1970s, when it was learned how blood plasma products could provide some effective treatment for haemophiliacs in ways that had not been possible before. Sadly, as we know, during that period the majority of regularly treated patients with haemophilia were unfortunately infected with HIV or hepatitis C, or possibly both. As a result, around 3,000 people with haemophilia are now estimated to be living with hepatitis C, 500 of whom are also infected with HIV. We all recognise that they therefore face considerable medical and psychological problems over and above those faced ordinarily by people with haemophilia.

Across the Chamber—and, clearly, within government—there is considerable sympathy for people with haemophilia in this situation. As the noble Lord, Lord Astor, said, it is essential that the NHS is properly geared up to deliver the full range of clinical and support services to help them, as far as possible, to cope with those afflictions. That includes providing routine and emergency medical treatment, drug therapies, physiotherapy, counselling and genetic services and specialised services for HIV and hepatitis.

The treatment and care of haemophilia patients is provided by a network of comprehensive care centres and smaller haemophilia centres. Significant progress has been made in the quality of care over the past 10 years or so. CCCs provide specialised care and support for patients and their families, delivered by multi-disciplinary teams. I shall deal later with the question raised by the noble Lord, Lord Astor, about the South West. All haemophilia patients who need that level of support should have access to the facilities of a comprehensive care centre, although it may not be geographically as close as some would desire.

The Government are also looking to develop a national service specification to try to ensure the highest possible standards for care. The Haemophilia Alliance, which includes the Haemophilia Society and the UK Haemophilia Centre Doctors Organisation, has produced its proposed national service specification, which outlines the key components of a high quality haemophilia service, whether it is provided in large CCCs or smaller haemophilia centres. The specification builds on the considerable expertise of the Haemophilia Alliance in delivering multi-disciplinary comprehensive patient care. The Government are determined to ensure that people with haemophilia are increasingly well cared for in the NHS, supported in their communities and more fully informed about how best to look after their health. We have welcomed that model service specification, which sets out clear standards of care for patients with inherited bleeding disorders. NHS commissioners of haemophilia services should find the document a valuable resource when planning and developing services for patients.

The treatment of hepatitis C has improved markedly over recent years. NICE assessed the use of a drug combination therapy of ribavirin and interferon for treating hepatitis C and published its recommendations in October 2000. This therapy has been shown to be twice as effective as any previous treatment. NICE's recommendations provide clear and authoritative advice for clinicians and healthcare providers and should help to ensure that patients get effective progress.

The thrust of the Government's position—as I am sure the House will expect—is that we do not believe that there are grounds for changing our position on compensation. Nevertheless, the focus has to be on trying to improve the quality of care that is offered. I shall briefly illustrate a number of facts—which I hope are accepted—about care and prognosis. It would be a mistake to create an impression that anyone unfortunate enough to have haemophilia and hepatitis C would inevitably die earlier than might otherwise be the case. The majority of patients who acquire hepatitis C will live out their normal life span. Hepatitis C infection is cleared in about 20 per cent of those infected, but it persists in about 80 per cent to become chronic infection. Most of those 80 per cent with chronic infection will have only mild liver damage and many will have no obvious symptoms. However, about 20 per cent of patients with chronic infection develop cirrhosis after 20 or 30 years. Out of 100 people exposed to hepatitis C, 20 would clear the virus within two to six months and 80 would develop it. Of those 80, 20 would never develop liver damage and 60 would develop some level of long-term symptoms. Of those 60, 24 would clear it fully and 16 would develop cirrhosis of the liver over 20 years.

None of that is to imply that this is a happy picture. Both having those diseases and undergoing the treatment regimes are distressing and painful for patients and their families. However, the figures show that the picture is not as bleak as might sometimes be imagined from some of our discussions. The thrust has to be to try to improve the prognosis for people who have been unfortunate enough to be afflicted in these ways.

On a national strategy to deal with hepatitis C, the noble Lord, Lord Astor of Hever, signalled the importance of high standards of medical and social care being applied consistently across England, if not across the United Kingdom, as this is clearly a devolved matter for Scotland and Wales. We fully recognise the importance for public health of having effective prevention, treatment and testing services in place for hepatitis C. We are committed to having a robust and

effective strategy to reduce transmission and benefit those already infected. To assist in developing our strategy, we set up a multi-disciplinary steering group in March 2001. We have asked the group to provide a draft strategy consultation paper for the Government to consider. We hope that it will be published in the next few months. The steering group has invited key stakeholders, of whom the Haemophilia Society will be an extremely important one, to provide information and advice. I know for a fact that it will comment vigorously.

The consultation paper will provide a framework for strengthening prevention, reducing the level of undiagnosed infections, improving services for patients with hepatitis C and identifying actions to support change. It is anticipated that the implementation of the strategy will be a component of the hepatitis action plan as proposed in the Chief Medical Officer's report.

I turn to the question raised by the noble Lord, Lord Astor, on treatment and haemophilia care in the West Country. As I think he indicated, there is not a comprehensive care centre in the South West, but there are haemophilia centres in Barnstaple, Exeter, Torquay, Plymouth and Truro. These are not comprehensive care centres but comprise the lower stage which do not have every single specialism but are able to deal with much of the medical and social support that families or individuals require. Nevertheless, that still means that perhaps once or twice a year a person with haemophilia and HCV may have to travel outside the region for other care. That is not done simply for reasons of economy; it involves critical specialist functions. Some of these centres need to have sufficient throughput to be able to retain and utilise specialist consultants to provide effective care. That is a highly relevant factor as regards why there is not such a centre in the South West.

The noble Lord, Lord Astor of Hever, also referred to a document which I assure the House is not the Government's consultation paper on the national strategy for hepatitis C, which will be published later this year as I have just indicated. It is, in fact, draft guidance for local authorities and the NHS specifically on blood borne viruses and children in need as defined by the Children Act 1989. We shall have to wait a little while before we see the consultation document itself.

I turn to the significant issue of recombinant clotting factors and their availability for all haemophilia patients. As the House knows, the lives of people with haemophilia were transformed in the 1970s by the development of clotting factors which brought the prospect of a much improved quality of life. However, as we know, these were infected. Everything has been done to ensure that the plasma-derived clotting factors used by people with haemophilia are as safe as possible. Since the mid-1980s, human plasma used to make clotting factors has been treated to remove HIV and hepatitis. Since then, products have had a quite remarkably excellent safety record. As an additional precaution, with the onset of variant CJD, all human plasma derived clotting factors now used by the NHS are made from imported plasma to reduce any potential cross contamination.

However, as has been noted in debate by the noble Baroness, Lady Gardner of Parkes, the noble Lord, Lord Astor, and others, over the past 10 years new recombinant or synthetic clotting factors have been developed. The Haemophilia Society and others have petitioned us to make recombinant factor 8 and 9 the treatment of choice for people with haemophilia. The noble Lord repeated that call today. That is largely based on the ground that recombinant products are regarded as free from the risk of transmission of as yet unknown viruses and free from a theoretical risk of variant CJD.

Before the switch to imported plasma in 1998, the fears of people with haemophilia were heightened by the discovery that some of them had received clotting factors that included plasma from a patient who subsequently developed variant CJD. Although the risk of transmitting variant CJD through blood products remains theoretical, I can perfectly understand why that has caused distress to many people with haemophilia given the history of that condition. Four years ago the Government responded to those fears by requiring NHS trusts to provide recombinant clotting products for all haemophilia patients and children under 16. As I think has been said, currently all patients up to the age of 20 receive recombinant products. Around 55 per cent of all clotting factors used in England are recombinant factors.

As I think has been pointed out, Scotland and Wales, with their devolved powers in these matters, already provide that treatment for all haemophilia patients. However, as the noble Lord is aware, we are giving consideration to extending the provision of recombinant clotting factors for all haemophilia patients in England. We shall take a decision on that matter later this year. It is not being ignored. In the meantime all haemophilia patients are receiving effective treatments with either recombinant or plasma-derived clotting factors.

The noble Lord, Lord Astor of Hever, also drew attention to the question of what research was being undertaken in this field. The Medical Research Council has made about £4 million available for hepatitis research over the past five years. The Department of Health has made £2.5 million available for hepatitis research since 1996-97. Therefore, there is ongoing research, as there should be.

I turn to a most painful issue. I refer to the issue of compensation to haemophilia patients with hepatitis C. That issue has been raised many times in both Houses. However, the Government's position remains unchanged. Although we have enormous sympathy for the individuals affected by this tragedy, we do not believe that a special payments scheme is justified. I know that that will come as a disappointment to the noble Lord, Lord Addington, and to others who have argued for such a scheme this evening and on previous occasions. That matter rests on the fundamental principle that has been

mentioned several times in the House; that is, unless it can be shown that a duty of care is owed by an NHS body and that there has been harm, and the harm was caused by negligence, the Government do not believe that compensation should be paid.

**Lord Morris of Manchester:** My Lords, how can we then defend the continued existence of the Macfarlane Fund for people with haemophilia infected with HIV?

**Lord Filkin:** My Lords, I am about to come to that point.

**Lord Morris of Manchester:** My Lords, I hope that my noble friend will also be referring to the vaccine damage payments scheme.

**Lord Filkin:** My Lords, comparisons have been made between the decision not to offer special payments to haemophiliacs with hepatitis C and the special payments established in the late-1980s for haemophiliacs with HIV and the ex gratia payments we are making to people with variant CJD and their families. However, the Government recognise that there are significant and real differences between those situations. I believe that the party of the noble Lord, Lord Astor, when in government, also recognised that point as they reached the identical judgment as this Government in those situations.

In the case of HIV we need to think back to the circumstances of the late 1980s when HIV had a vast and dramatic effect. It was a source of massive fear and stigma for all those who became infected. There was widespread public reaction. There was no treatment known or thought to be possible for it and death from AIDS related diseases was considered inevitable for all people who had HIV. That is not the situation for those with hepatitis C. It was in that context that special payments were introduced and the Macfarlane Trust was established. We see that as a reflection of those truly exceptional circumstances and the poor prognosis at the time for people with haemophilia who became infected with HIV.

Although the Government have agreed ex gratia payments for victims of variant CJD, the circumstances and background of that situation are again truly exceptional. Variant CJD is a particularly horrific condition. It is incurable. It is inevitably fatal and it is devastating in its effect on sufferers and their families, both to know that one has it and in the form of dying that follows from it. That, fortunately, is not the situation with hepatitis C. It therefore, does not change our longstanding policy on compensation for injuries caused by the NHS which I firmly believe is the right one.

The noble Lord, Lord Morris, referred to Justice Burton's judgment. In short, the judgment effectively found that there was a liability between the period of time when it was possible to introduce a cure and a cure was introduced, and when it was covered by the 1998 Act.

Mention has been made of the policy and practice of other countries. Clearly, the Government are tracking the position closely. There is not time to give chapter and verse on every other country that has made judgments. The vast majority of countries do not make compensation for haemophiliacs with hepatitis C. Those countries that do, such as Canada and Ireland, particularly focus compensation on periods when they believed that they had negligence in relation to the delay in introducing treatment to blood plasma products after it was found possible to so treat them and reduce the risk of infection from hepatitis C.

The noble Lord called for a public inquiry. In essence, the Government's position on that is that there is nothing of fundamental significance that we do not know about a public inquiry that would be brought out by it. The Government did not take part in a whitewash in 1997-98. There was a serious attempt by officials and Ministers to look afresh at the decisions that were taken by the previous government to establish whether they raised anything that required to be considered afresh. That was done fully and carefully. I know that the noble Lord, Lord Morris, regrets the fact that the position was not changed.

Reference has been made to the position of the noble Lord, Lord Owen, as Minister responsible for health, in relation to self-sufficiency in blood plasma products. Again, time does not allow me to go into full details. However, the essence is that at that time all blood plasma products were infected, we believe, with hepatitis C, and whether they had been imported or not would not have fundamentally affected the vulnerability of haemophiliacs to infection, which all of us regret so deeply.

For those reasons, with regret, I do not believe that there is benefit to anyone from a public inquiry, and the Government therefore do not support that. However, to go back to where I started, there is continuing concern in the Government and across the House for the affliction of people who suffer haemophilia and hepatitis C or HIV with it. I have marked the fact that we shall be publishing a very serious national consultation strategy and I very much hope that there will be vigorous engagement with that in the coming months. Ministers will of course be very pleased to meet the Haemophilia Society and its president. We have the greatest respect for its work on behalf of the people who suffer from this very serious affliction.

## Haemophiliacs: Recombinant Treatment

6<sup>th</sup> February 2002

**Lord Morris of Manchester:** My Lords, I beg leave to ask the Question standing in my name on the Order Paper. I have an interest to declare, but not a financial one, as president of the Haemophilia Society.

The Question was as follows:

To ask Her Majesty's Government when they now expect to provide recombinant treatment for people with haemophilia irrespective of age or where they live in the United Kingdom.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):** My Lords, the Government are considering the case for extending the provision of recombinant clotting factors to all haemophilia patients in England.

**Lord Morris of Manchester:** My Lords, is it not cruelly wrong in principle that people with the same disability are given or refused safer medical treatment according to whether they live in Scotland and Wales or in England? And more especially so when contaminated blood products that were prescribed for them have already taken the lives of over 1,000 haemophiliacs in the NHS's worst-ever treatment disaster. Is it not also plainly wrong that even the current policy of entitling children in England to the safer recombinant treatment is sometimes ignored? What have Ministers done to protect such vulnerable children? When will right be done?

**Lord Hunt of Kings Heath:** My Lords, I acknowledge the force with which my noble friend and the Haemophilia Society have put forward the case over recent years. There is no evidence that recombinant clotting factors are more efficacious than plasma-based products. My noble friend is certainly right to suggest that policy varies in different parts of the United Kingdom, with Scotland and Wales committed to providing recombinant treatment for all haemophilia patients. As I said, we very much understand the concerns of the people who have been so tragically affected, and we are considering the position in England.

**Baroness Gardner of Parkes:** My Lords, is the Minister aware that patients with haemophilia are experiencing great difficulty in obtaining dental treatment? When those patients have been refused and have taken up the matter with the United Kingdom Haemophilia Centre Doctors Organisation, they have been told that the matter should be referred to the CJD Incident Panel. Is that because they are being treated with non-recombinant factor or would all haemophilia cases be so referred, and why are such referrals made to the variant CJD treatment centre?

**Lord Hunt of Kings Heath:** My Lords, I believe that the reference to variant CJD has come about because consultation on risk assessment in relation to the use of medical instruments has just concluded. However, I shall be happy to follow up this matter with the noble Baroness. If she has specific cases to bring to my attention, I shall certainly be prepared to look into them. In relation to access to dental treatment, I would also expect community dental services at local level to be asked to look into matters which affect people locally.

**Lord Addington:** My Lords, does the Minister agree that this matter concerns the basic safety of the treatment? As recombinant treatment is seen to be safer and more efficient, is it not the case that a group who historically have suffered so badly should receive that treatment straightaway?

**Lord Hunt of Kings Heath:** My Lords, I hear what the noble Lord says. As I said, the matter is being considered carefully by the Government at present. However, the advice that I have received is that there is no evidence that recombinant clotting factors are more efficacious than plasma-based products. But, of course, I recognise the feelings of those in the community and the fears of parents of children and, indeed, of all those who receive blood products through infectious agents. That is why the Government are considering the matter.

**Baroness Masham of Ilton:** My Lords, I also declare an interest as a vice-president of the Haemophilia Society. Is the Minister aware that in Newcastle upon Tyne 75 per cent of haemophiliacs have contracted HIV? In addition, bearing in mind the problems of CJD and hepatitis C, is it not time that haemophiliacs were given the safest possible form of clotting agents?

**Lord Hunt of Kings Heath:** My Lords, I do not believe that I can add to the response that I gave to the noble Lord. As I said, the advice that I have received is that as yet there is no evidence to suggest that there is an issue of safety between the different products. We understand the feelings of those in the community who are involved and affected by the tragic events that have occurred. We are obviously considering the matter.

**Lord Turnberg:** My Lords, if it is now possible for the manufacturers of recombinant factor 8 to produce a sufficient amount of the treatment for everyone who might need it, is there now any reason why that material should not be available to all haemophiliacs, regardless of age?

**Lord Hunt of Kings Heath:** My Lords, my noble friend is right in identifying that a shortage of recombinant factor 8 has limited supplies to the UK over the past year. My understanding is that that shortage has now eased up and that manufacturers have increased production. Obviously that is one of a number of issues that needs to be taken into account.

**Lord Clement-Jones:** My Lords, if the Minister and his colleagues are prepared to consider beta interferon for MS sufferers, why should the Government not enter into a novel risk-sharing arrangement over recombinant clotting factors as they have done in relation to beta interferon?

**Lord Hunt of Kings Heath:** My Lords, that is certainly an interesting suggestion. I would say only that at present these matters are under consideration by the Government.

**Lord Morris of Manchester:** My Lords, further to my noble friend's reply to the noble Baroness, Lady Gardner, can he tell the House how many people with haemophilia have received blood that was donated by donors who have since died of variant CJD?

**Lord Hunt of Kings Heath:** My Lords, the figures so far are that eight people with variant CJD are known to have been blood donors and 22 people have been identified as having received transfused blood from donors who later developed variant CJD. I understand that the total number of deaths from variant CJD is 106.

**Earl Howe:** My Lords, have the Government estimated the additional cost of recombinant treatment to haemophiliacs were it to be available in England?

**Lord Hunt of Kings Heath:** My Lords, the cost that has been made available to me is in the region of £50 million a year.

## Hepatitis C

15 October 2001

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

What further consideration they are giving to the Haemophilia Society's call for a public inquiry into the infection of haemophilia patients with hepatitis C by contaminated National Health Service blood products.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):** My Lords, the Government have great sympathy with haemophilia patients who were infected with hepatitis C before the means existed to remove the virus from blood products. We have given careful consideration to the call for a public inquiry but do not believe that that is the way forward. The facts have been set out clearly on many occasions in debates in both Houses, in meetings with Ministers from the Department of Health and in correspondence.

**Lord Morris of Manchester:** My Lords, is it not grossly damaging to the reputation of the National Health Service that we still await a public inquiry into its worst-ever treatment disaster—one that has already taken more than 100 lives among the now more than 1,000 haemophilia patients who have died from contaminated NHS blood products? And will my noble friend respond to the deeply disquieting recent disclosure made by my former ministerial colleague, the noble Lord, Lord Owen, to the BBC's "Face the Facts" programme, when he said that money laid aside, when he was health Minister, to protect haemophilia patients from infection from blood-borne infection was diverted to other purposes? Is this not still further evidence that an in-house departmental inquiry is no substitute for the public inquiry the Haemophilia Society is seeking?

**Lord Hunt of Kings Heath:** My Lords, I believe that all the facts have been produced in various debates in your Lordships' House and in the other place. There can be no doubt that any Minister who had a decision to make on the issue cannot but deeply regret that so many people with haemophilia were infected with hepatitis C through blood products. As soon as the technology became available to make blood products free from hepatitis C, it was introduced by the National Health Service.

I have asked officials to look into statements made by the noble Lord, Lord Owen. We shall respond to those statements in due course. My understanding is that the resources promised by the noble Lord when he was Minister of Health were allocated to the then regional transfusion centres to increase production of plasma for the bioproducts laboratory. That resource was used and, as a result, production was increased considerably. However, because of the rapid growth in demand for those products we did not achieve self-sufficiency in this country. Even if that was achieved in the late 1970s, the fact that heat treatment did not take place until the mid-1980s meant that self-sufficiency would not have prevented haemophiliacs being infected with hepatitis C.

**Lord Clement-Jones:** My Lords, can the Minister tell the House what moral distinction the Government make between their decision to set up a £60 million compensation fund for those who contracted new variant CJD and their adamant refusal to do the same for those who contracted hepatitis C through contaminated blood products? Is that not a case of double standards?

**Lord Hunt of Kings Heath:** No, my Lords. Such decisions are always difficult and no Minister would ever make them lightly. The plight of individuals and families affected by new variant CJD was the result of a unique set of circumstances. The Government considered that society as a whole should bear a moral responsibility. New variant CJD is a particularly distressing condition. Even though we were advised that we were unlikely to be legally liable, we considered it right to make payment to the victims and their families.

**Baroness Gardner of Parkes:** My Lords, can the Minister tell the House whether the situation in this country is different from that in France where I understand that the Government knowingly allowed HIV-transmissible injections to be used for haemophiliac patients? I believe that one of their Ministers admitted to that. Are we sure that that was never knowingly done in this country? Can the Minister tell the House the number of relative cases of hepatitis C as opposed to the number of HIV/AIDS cases that have been transmitted to haemophiliacs through blood products?

**Lord Hunt of Kings Heath:** My Lords, clearly, circumstances have differed in every country which has had to face up to this problem. In the early 1970s, clinicians knew that there was a risk of hepatitis. However, there was great demand and, indeed, enthusiasm, for the new treatment from haemophiliacs and doctors. The impact of hepatitis C was not fully understood at that time and its effects were unclear. It was not until the mid-1980s and the attempt to prevent HIV that heat treatment was first used. It was not until then that there was a process which could have prevented the hepatitis C infection.

#### Hepatitis C

23<sup>rd</sup> April 2001

**Lord Morris of Manchester** rose to ask Her Majesty's Government what further help they are considering for people who were infected with hepatitis C by contaminated National Health Service blood products and the dependants of those who have since died in consequence of their infection.

The noble Lord said: My Lords, the scriptures tell of,

"a man of sorrow and acquainted with grief".

This debate is about a whole community in sorrow and for whom acquaintance with grief--recurrent and often abject grief--is an inescapable fact of daily life. So too is a burning sense of injustice.

To work with and for the **haemophilia** community--as I have the honour to do as President of the **Haemophilia Society**--is at once humbling and inspiring. I say this as a serial legislator on the problems and needs of disabled people for over 30 years now, both as their first-ever Minister and the author of successful Private Members' Bills--twice chairing the international committee that informed UN pronouncements on disability rights--and thus having worked with people with severe disability in all its forms world-wide.

And I know of no disability group anywhere whose courage, fortitude and moral strength exceed those of Britain's **haemophilia** community in facing what doctors of the highest distinction--including some noble Lords--see as the worst treatment disaster in the history of the National Health Service.

That my noble friend Lord Burtison is again on duty in this debate, as he was to respond to the exchanges about the disaster on my Starred Question on 26th March, is most welcome to me on personal grounds. For I have long held him in the highest regard. He will, though, understand that the further absence this evening of the noble Lord, Lord Hunt, as a Health Minister, will be disquieting to the **haemophilia** community, more particularly in view of the Prime Minister's letter of 30th January to Eddie O'Hara MP--copied to me and clearly also to my noble friend--about compensation for people with **haemophilia** infected with hepatitis C, which stated that,

"Lord Hunt in the Department of Health has responsibility for this policy issue".  
My noble friend Lord Burlison will, I am sure, want to explain, when he comes to reply this evening, why the Minister cannot attend a debate that is so very important to the haemophilia community.

Already disabled by a rare, life-long bleeding disorder requiring continuous medical treatment—for which there is no cure—people with haemophilia have twice been infected en masse by unclean NHS blood and blood products. Of a community of 6,000 people, some 4,000 were infected with hepatitis C (HCV), of whom 1,240 were also infected with HIV. Of those with HIV infection 818 have since died of AIDS-related illnesses; and well over 100 of those infected with HCV alone have in consequence died of cirrhosis and liver cancer. Now there is what is officially described as a "theoretical" risk that hundreds of people with haemophilia have been infected yet again, this time with variant CJD by a blood donor who has since died of the disease.

Almost everyone with haemophilia now over 15 was infected with HIV and HCV by unclean NHS blood and blood products; and of a haemophilia community of some 6,000, now approaching 1,000 have died of one or other of these two life-threatening viruses. Others are now in very poor health, many of them terminally ill, and have lost their jobs, homes and, in some cases, family due to infection.

Among those not so far seriously affected, there is the daunting worry of not knowing which of them will develop AIDS-related illnesses or chronic liver disease. No one with HCV infection, regardless of their health now, can obtain life insurance except at prohibitive rates. And excluding them from help from the Macfarlane Trust denies those with young families and other dependants even the peace of mind of knowing that, if they become terminally ill, they will be provided for.

Yet there is still no positive response from Ministers to the Haemophilia Society's calls for an independent public inquiry into this appalling disaster and the provision of financial help for its victims. This compounds their sense of injustice. They see themselves as forgotten, cast aside as "yesterday's people": too small and powerless a community to be treated as politically important in a society that is being told more and more insistently from Whitehall how economically strong and affluent Britain has now become.

There have been sympathetic words from successive governments. But as a member of the Haemophilia Society now suffering the cruelly punitive effects of end-stage HCV, told me recently:

"It is not sympathy we want from Governments—it is justice—and I find it heartless and unforgivable that they still refuse us even a public inquiry".

It should not be necessary for me to have to make this further plea for elementary justice for sick and deeply vulnerable people now living under a death sentence for the mistake of having trusted in the cleanliness of NHS blood and blood products. After all, when the Green Paper on Welfare Reform was published on 26th March 1998, Ministers told both Houses of Parliament that the Government's,

"commitment to the vulnerable is non-negotiable".

That ringing declaration raised hopes nowhere more visibly than in the haemophilia community. For no Minister who has spoken to anyone trying to cope with end-stage HCV can doubt their vulnerability or that of their dependants. Indeed, the word "vulnerable" might have been invented to describe them.

That no public inquiry has yet been held into a medical disaster on this scale—leaving 95 per cent of patients with the devastating complications of two life-threatening viruses—is without precedent in the modern era. And it does nothing to assuage the anguish and anger of the victims and their dependants to hear Ministers saying that so grave a disaster is now best forgotten; that it is time to "draw a line" under what happened; and that the haemophilia community should "move on". Indeed, they regard such statements as offensive and bereft of any understanding of the extent of sorrow and grief in their small, closely-knit community as more and more of them become terminally ill and die of infection by unclean NHS blood products. Yet fortunately they are not without friends good and true, as I was reminded again this morning by a deeply well informed and very moving letter of support for them from Vicky Vidler, who chairs the Royal College of Nursing's Haemophilia Nurses' Association.

In effect, people with haemophilia given NHS blood products in the 1970s were human guinea-pigs for a new form of treatment. The risks were not explained to them; and despite the scientific knowledge then available to Whitehall that hepatitis could be transmitted in blood, no warnings were given to enable haemophilia patients to make an informed choice.

However, no one has been held to account and no apology has been made. There have quite rightly been public inquiries into the spread of BSE, paediatric cardiac care in Bristol and the retention of human tissue at Alder Hey. Public inquiries have also been held, again quite rightly, into the sinking of the "Marchioness" and the Paddington rail disaster. But far more people have died through the mass infection of haemophilia patients than in all these cases. Why, then, does this much bigger disaster not merit a public inquiry?

For the Department of Health's own "internal inquiry"--which tersely reported in 1998--to be seen in Whitehall as any kind of substitute for a public inquiry is also offensive to the haemophilia community. Reputable journalists freely describe this caricature of an inquiry as,

"a whitewash perpetrated behind closed doors". Its findings were demonstrably flawed. They again peddled the fallacy that, unlike HIV, hepatitis C does not involve social stigma; and they simplified the last government's reasons for compensating only HIV infection to the point of crude inaccuracy. At any public inquiry its findings would have been summarily repudiated. Indeed, what the department's in-house "inquiry" did was to make the case for an independent public inquiry into the disaster all the more compelling and it is indefensible that we are still left waiting for that inquiry.

The Haemophilia Society has given Ministers evidence galore that the stigmatising of those with hepatitis C by people who fear they too could become infected is every bit as strong as that of HIV infection. Also like those infected with HIV, but without compensating help from the Macfarlane Trust, they have the same lack of access to financial services. Yet current medical opinion suggests that up to 80 per cent of them will develop chronic liver disease; and that up to 25 per cent may develop cirrhosis, which can progress to liver cancer.

The HCV virus progresses more slowly than HIV. It can take 20 to 30 years but, once active, it is highly dangerous. Nevertheless, those infected are left to cope unhelped by the Macfarlane Trust created to help others in the same plight. And the only fair and just way forward is to extend the trust's remit to end the inequity that now so illogically divides the haemophilia community.

The setting up of the Macfarlane Trust for HIV-infected people was an acceptance of moral responsibility for their loss and hardship. An exception was made from normal NHS practice in regard to medical negligence and legal liability for people who were infected with that life-threatening virus. And the present Government, who came to power committed to higher moral standards, must do no less now for others infected by another life-threatening virus in the same small community, at the same time and by the same route. There is exactly the same moral responsibility for loss and hardship in the two cases. Yet as this Parliament approaches its fifth year parity is still denied.

The NHS was founded on a moral principle in which we on these Benches can take special pride. But as my noble friend Lord Winston, Vice-President of the Haemophilia Society, has said:

"Moral principles impose obligations and responsibilities; and there is a price as well as an advantage in taking the moral high ground". The last government paid that price in the case of HIV infection. The moral promise on which this Government came to power alone commits us to do the same now for people infected in the same way with HCV.

Notwithstanding the creation of the Macfarlane Trust to compensate for HIV infection, Health Ministers still repeatedly state that, for compensation to be awarded, the NHS must be found to have been negligent. This was stated yet again on 29th March (cols. 410-11) after my noble friend Lord Peston had said that he did not understand the Government's ethical position in regard to HCV infection.

"On all sorts of grounds which once, at least, our party used to believe", he said,

"compensation is exactly the right path to take". But in response, my noble friend Lord Hunt, speaking for the Department of Health, strongly insisted that compensation could not be awarded unless it could be,

"shown that a duty of care is owed by the NHS body; that there had been negligence; that there had been harm; and that the harm was caused by the negligence".--[Official Report, 29/3/01; cols. 410-11.] But that is not so. His brief was wrong. Moreover, had it been right, as Karin Pappenheim, Chief Executive of the Haemophilia Society, has aptly responded:

"It would mean that under this Government--on the strength of their decisions on HCV infection to date--there would have been no Macfarlane Trust at all".

This and other Labour Governments have not, of course, uniformly insisted on proof of medical negligence before compensating NHS patients. For example, payments under the vaccine damage payments scheme, introduced when my noble friend Lord Callaghan was Prime Minister, have been substantially increased by the present Government, just as they have also increased the Macfarlane Trust's funding. Another example of their readiness to compensate without legal liability is the financial help recently agreed for British survivors of Japanese prisoner-of-war camps.

And indeed 27 years ago, the then Labour Minister for War Pensions changed the law to give benefit of doubt where ex-servicemen with cardiothoracic illnesses, having served in a theatre of war where gas was used as a weapon of war, applied for war pensions or their widows for war widows' pensions. I well recall this further example because I was the Minister who took that decision; and I did so without any prompting from its beneficiaries. So I speak in this debate as the advocate not of a new departure in social policy but of due respect for honourably humane precedent.

In truth, the issue is not one of inflexible rule but of political will and priorities. And I suspect that few of us here, or in another place, would have to "ask the audience" or "phone a friend" to discover the right thing to do in this case.

There are two more issues I want briefly to address. The first concerns the game of Russian roulette now being played with the haemophilia community. Despite the gruesome history of contaminated NHS blood, the vast majority of people with haemophilia over 16 are still made to rely on plasma-based products, rather than the safer--but more costly--genetically engineered recombinant Factor 8 or 9. But the Department of Health still sees nothing wrong in making them accept the "theoretical" risk of using plasma-based blood products, even although risks they have already been forced to face proved far from "theoretical". In approaching 1,000 cases they were deadly.

What possible justification is there for denying them the safer treatment? In Scotland and Wales it is already available as of right to everyone in need: children and adults alike. In England it is provided for people over 16 only if they are fortunate enough to live in the right area. And this cruelly discriminatory policy is made all the more shocking by the potentially grave further risks of blood-borne infection now revealed by the recent disclosure that plasma from a man later diagnosed with vCJD was used in 1996 and 1997 to manufacture haemophilia treatment.

Here again, the risk is played down by officials. The department's Chief Medical Officer is quoted as saying that the risks of vCJD infection are "purely theoretical". But these words offer no comfort to parents in shock from knowing their child has been treated with plasma derived from a donor with vCJD. They and others ask why--if the risks are in fact "purely theoretical"--it should have had to be put to the test by people already twice infected by other "theoretical" but lethal risks? Only a ministerial pledge to make the safer treatment available to everyone will be acceptable. The Haemophilia Society has repeatedly called for that pledge and this debate is an appropriate occasion for it to be given.

I come now to Mr Justice Burton's landmark High Court judgment on 26th March. His core finding was that the supplier of blood to NHS patients has a legal duty to supply clean blood and significant compensation was awarded. Yet some 4,000 people with haemophilia were supplied with unclean blood and blood products and, while the judgment applies directly only to offences after the Consumer Protection Act came into effect in March 1988, any attempt to deny its benefits to the haemophilia community would provoke moral outrage.

The unmistakable logic of the High Court's judgment is that it is right in principle to compensate NHS patients infected by unclean blood; and unless that logic is accepted and applied to the haemophilia community, any continuing ministerial claim to the moral high ground is plainly untenable. For without question the issue is one of moral right; and in none of the parliamentary campaigns in which I have been involved in over 37 years in Parliament--even thalidomide and that for statutory recognition of dyslexia--have I felt so strongly that campaigning ought not to have been necessary.

There has been enormous all-party backing by MPs for Motions calling for equality of treatment to end the gratuitously added distress now imposed on many of the most needful victims of the historic tragedy of unclean blood. I especially recall now that Alan Milburn, the present Health Secretary, was among the signatories of a Motion tabled in another place in my name calling for exactly what I seek in this debate. That Motion, like all the others, made it plain that this is not an issue for party animus--of right and left--but one of right and wrong.

Most of all this evening, I urge Ministers not to demean this House and another place by making legal action, here or internationally, the only way to resolve an issue that is so obviously one of social decency and moral right. Knowing as they will the outcome of the legal action taken on behalf of the haemophilia community in France, I suspect that my preference for resolving this issue, if at all possible, by other than legal means will be shared by health officials here.

In France two senior officials, Dr Michel Garretta and Dr Jean-Pierre Allain, were convicted and sentenced to four years in prison and ordered to pay the sterling equivalent of £1.2 million on charges of "distributing tainted blood" that infected more than 1,250 French haemophilia patients, 273 of whom have since died. A third senior health official was given a four-year suspended sentence—but still heavily fined—and the Health Ministers resigned "in disgrace".

But my call in this debate is not to inflict retribution on public servants. It is simply to achieve social justice for a small but grievously hurt community. I ask of Ministers only that they should now let right be done and in its proper setting: here in Parliament.

**Lord Clement-Jones:** My Lords, I believe that the House should heartily thank the noble Lord, Lord Morris, for raising this issue yet again. It is unfortunate that I should have to congratulate the noble Lord on his dogged persistence in raising this issue time and time again. I can remember at least two previous debates this time last year and another in 1998. I remember innumerable Starred Questions on the subject, and yet the noble Lord must reiterate the same issues and points time and time again in debate. It is extremely disappointing that tonight we hold yet another debate to point out the problems faced by the haemophilia community as a result of the infected blood products with which the noble Lord has so cogently dealt tonight.

Many of us are only too well acquainted with the consequences of infected blood products which have affected over 4,000 people with haemophilia. We know that as a consequence up to 80 per cent of those infected will develop chronic liver disease; 25 per cent risk developing cirrhosis of the liver; and that between one and five per cent risk developing liver cancer. Those are appalling consequences.

Those who have hepatitis C have difficulty in obtaining life assurance. We know that they have reduced incomes as a result of giving up work, wholly or partially, and that they incur costs due to special dietary regimes that they must follow. We also know that the education of many young people who have been infected by these blood products has been adversely affected. The noble Lord, Lord Morris, was very eloquent in describing the discrimination faced by some of them at work, in school and in society, and their fears for the future. He referred to the lack of counselling support and the general inadequacy of support services for members of the haemophilia community who have been infected in this way.

There are three major, yet reasonable, demands made by the haemophilia community in its campaign for just treatment by the Government. To date, the Department of Health appears to have resisted stoically all three demands. First, there is the lack of availability on a general basis of recombinant genetically-engineered blood products. Currently, they are available for all adults in Scotland and Wales but not in England and Northern Ireland. Do we have to see the emergence of a black market or cross-border trade in these recombinant products? Should not the Government make a positive commitment to provide these recombinant factor products for all adults in the United Kingdom wherever they live? Quite apart from that, what are the Government doing to ensure that the serious shortage of these products is overcome? In many ways that is as serious as the lack of universal availability. Those who are entitled to them find it difficult to get hold of them in the first place.

The second reasonable demand of the campaign is for adequate compensation. The contrast with the HIV/AIDS situation could not be more stark. The noble Lord, Lord Morris, referred to the setting up of the Macfarlane Trust which was given £90 million as a result of his campaigning in 1989. The trust has provided compensation to people with haemophilia who contracted HIV through contaminated blood products. But there is no equivalent provision for those who have contracted hepatitis C. The Government, in complete contrast to their stance on AIDS/HIV, have continued to reiterate that compensation will not be forthcoming. The Minister of State for Health, Mr Denham, said some time ago that at the end of the day the Government had concluded that haemophiliacs infected with hepatitis C should not receive special payments. On 29th March of this year the noble Lord, Lord Hunt, in response to a Starred Question tabled by the noble Lord, Lord Morris, said:

"The position is clear and has been stated policy by successive governments. It is that, in general, compensation is paid only where legal liability can be established. Compensation is therefore paid when it can be shown that a duty of care is owed by the NHS body; that there has been negligence; that there has been harm; and that the harm was caused by the negligence".—[Official Report, 29/3/01; col. 410.]

The Minister said something very similar on 26th March. This means that the Government have refused to regard a hepatitis C infection as a special case despite the way in which they have treated AIDS/HIV sufferers who, after all, were adjudged to be a special circumstance. These are very similar situations.

In our previous debate on this, noble Lords referred to the similarity between the viral infections. They are transmitted to haemophiliacs in exactly the same manner; they lead to debilitating illness, often followed by a lingering, painful death. I could consider at length the similarities between the two viral infections and the side effects; for example, those affected falling into the poverty trap. We have raised those matters in debate before and the Government are wholly aware of the similarities between the two infections.

The essence of the debate, and the reason for the anger in the haemophilia community, is the disparity in the treatment of haemophiliacs infected with HIV and those who, in a sense, are even more unfortunate and have contracted hepatitis C. We now have the contrast with those who have a legal remedy, which was available as demonstrated in the case to which the noble Lord, Lord Morris, referred, and are covered by the Consumer Protection Act 1987. This latter case was in response to an action brought by 114 people who were infected with hepatitis by contaminated blood. The only difference between the cases that we are discussing today and the circumstances of those 114 people is the timing. Is it not serendipity that the Consumer Protection Act 1987 covers those 114 people but not those with haemophilia who are the subject of today's debate?

It is extraordinary that the Government—I have already quoted the noble Lord, Lord Hunt—take the view that it all depends on the strict legal position. Quite frankly, the issue is still a moral one, as we have debated in the past. In fact, the moral pressure should be increased when one is faced with the comparison with both that case and the HIV/AIDS compensation scheme. People with haemophilia live constantly with risk. We now have the risk of transmission of CJD/BSE. What will be the Government's attitude to that? Will they learn the lessons of the past? I hope that the Minister will give us a clear answer in that respect.

I turn to the third key demand of the campaign by the haemophilia community. Without even having had an inquiry, the NHS is asserting that no legal responsibility to people with haemophilia exists. The Government's position—that they will not provide compensation where the NHS is not at fault—falls down because that is precisely what the previous administration did in the case of those infected with HIV. An inquiry into how those with hepatitis C were infected would perhaps establish very similar circumstances.

Other countries such as France and Canada have held official inquiries. Why cannot we do the same in this country? The Government's refusal to instigate a public inquiry surely fails the morality test. Surely the sequence of events which led up to what has been widely referred to as one of the greatest tragedies in the history of the NHS needs to be examined with the utmost scrutiny. Why do the Government still refuse to set up an inquiry? Is it because they believe that if the inquiry reported it would demonstrate that the Government—the department—were at fault?

Doctors predict that the number of hepatitis C cases among both haemophiliacs and the general population is set to rise considerably over the next decade. The Department of Health should stop ignoring the plight of this group. They should start to treat it fairly and accede to its reasonable demands. The Government's attitude to date has been disappointing to say the least. This debate is another opportunity for them to redeem themselves.

**Lord Astor of Haver:** My Lords, like the noble Lord, Lord Clement-Jones, I, too, thank the noble Lord, Lord Morris of Manchester, for initiating this important debate. It is always a great pleasure to speak in a debate initiated by the noble Lord. I, too, pay tribute to him for his dogged persistence in returning again and again to this cause about which he has spoken so movingly today. The Haemophilia Society is indeed fortunate to have him as its very effective president.

We on these Benches share his concern for the plight of those haemophiliacs who received infected blood products before the hepatitis C infection could be removed. People with haemophilia are a small but vulnerable patient group who, through no fault of their own, have suffered a lot. We feel a great deal of sympathy for them. I agree with the noble Lord, Lord Morris, that they have shown incredible courage, fortitude and moral strength.

We, on these Benches, have always argued against no-fault compensation for medical accidents in the NHS. But we feel that there are a number of ways in which the Government can and should be helping these unfortunate people.

First, haemophilia sufferers should be treated equally, irrespective of where they live. That is not happening. Comprehensive care centres provide specialised care and support for patients and their families. However, as the noble Lord, Lord Clement-Jones, said, the provision of these centres is uneven. They are also subject to postcode rationing. Some NHS regions have several care centres while others are under-provided. The South West has none. For haemophiliacs living in Cornwall or Devon the nearest centre is in Basingstoke, Hampshire, 237 miles from Penzance. The Trent region, however, has four centres.

During the course of the debate in November last year in the name of my noble friend Lord Howe, the Minister, the noble Lord, Lord Hunt, told the House that the Haemophilia Alliance was developing a national service specification to help standardise all aspects of haemophilia services. This was intended to get rid of unacceptable variations in care. I understand that the Government are still considering the representations. Can the Minister tell the House when the specification might be published?

I also understand that the Government are setting up a hepatitis C expert-steering committee which will produce an important consultation document. How wide a remit, and how much authority, will that document have over the wide range of specialist services including haemophilia which treat, support and care for people with hepatitis C?

There is currently no nation-wide system to identify and monitor all people with haemophilia infected with HCV. What plans do the Government have to ensure that, in the interests of the safety and well being of this patient group, such a system is created?

The majority of health authorities either do not provide treatment for HCV or only on a limited and inadequate scale. The combination therapy, involving Interferon alpha and Ribavirin, which is able to cure up to 40 per cent of patients, costs some £9,600 per annum per patient. Although NICE recommended that patients suffering from moderate or severe HCV should be given the combination therapy, there are concerns that the NICE guidance will not be enough to solve the postcode lottery. This is gambling with lives--and despite repeated assurances from Ministers that people with haemophilia would not be denied treatment for HCV. Timely drug treatment does reduce the long-term costs of care, particularly the need for expensive liver transplants. Can the Minister tell the House how the Government intend to honour these ministerial assurances?

We believe that the barrier to funding relatively expensive drug therapies could be eliminated by the creation of a central funding mechanism for such exceptional medicines quite separate from health authority budgets. I know that the Minister, the noble Lord, Lord Hunt, has reservations on this score. However, it is unlikely that health authorities will follow NICE guidelines despite the additional resources which have been put into the health service. I should be grateful to know, therefore, whether the Minister's department has further reviewed our suggestion to ensure that people with haemophilia are not refused their only hope of a cure. It cannot be right that there is unequal access in different areas to this treatment.

As the noble Lord, Lord Clement-Jones, pointed out, there are fears that the Government are putting haemophiliacs in England at risk from vCJD. In England, unless they are new patients, or under 16, haemophiliacs must use blood products derived from human blood with all the risks, including CJD, which this might entail. Haemophilia sufferers in Scotland, Wales and Northern Ireland, on the other hand, are given the safe, genetically-produced, recombinant Factor 8. This is also postcode care for haemophiliacs.

This is most apparent in the English haemophilia centres in Liverpool and Manchester to which patients from North Wales go for treatment. The policy adopted by the NHS commissioners in Wales means that all haemophiliacs living in North Wales are entitled to receive recombinant Factor 8 irrespective of age, postal code or viral status, and attend the Manchester or Liverpool centres. However, many people living in Manchester, Liverpool and the surrounding areas do not have the same rights and benefits. The Government must now stop treating haemophiliacs in England as second-class citizens. After all, as the noble Lord, Lord Morris, said, the Government came to power on a commitment to the vulnerable that is non-negotiable.

I therefore ask the Minister what plans the Government have to ensure that plasma-derived treatments are successfully screened for new variant CJD. What reason is there for further denying to adult haemophilia sufferers in England the safer recombinant clotting factors? Was the decision to withhold this treatment taken on financial or clinical grounds? Was it because there is a world shortage of recombinant Factors 8 and 9? If that is the case, what representations are the Government making on behalf of the haemophilia community to secure a full supply to the UK as soon as possible?

There seems to be a lack of welfare support for many haemophilia sufferers. I have received several reports of a lack of information in DSS offices at a local level. I am aware that the Minister is not a DSS spokesman. However, it would be helpful to have some reassurance that this problem will be looked at.

We feel that far more funding is needed for research. There is much about HCV that remains unknown. The precise mechanisms by which HCV causes liver cancer have not been identified. We still need a simple, cost effective and reliable diagnostic assay test, both for the initial detection of HCV and for monitoring the disease as it progresses. Perhaps the Minister can touch on funding for research when he winds up.

The noble Lords, Lord Morris and Lord Clement-Jones, both mentioned in some detail the High Court judgment made by Mr Justice Burton. Doubtless the Minister will comment on the Government's response.

I much look forward to the Minister's remarks in winding-up, particularly as I have lobbed him a formidable number of questions. I quite understand that he may not be able to answer them all tonight, but perhaps he could respond by letter to the others.

**Lord Burlison:** My Lords, I join noble Lords in thanking my noble friend Lord Morris of Manchester for raising this issue. After hearing his submission today, no one can be in any doubt of the noble Lord's commitment to this cause. Like other noble Lords, I know that, as president of the Haemophilia Society, he will pursue this issue in a dogged fashion until he makes progress generally on behalf of that society.

Perhaps I may also assure your Lordships that my noble friend Lord Hunt of Kings Heath, like myself, feels very strongly about the issue. The fact that this debate has taken place tonight demonstrates yet again the strength of feeling within this House on behalf of people with haemophilia and hepatitis C.

Haemophilia is a lifelong, painful and debilitating condition. But modern treatment is very effective, with patients now able to look forward to a good quality of life. Sadly, during the late 1970s and indeed the 1980s, the majority of regularly treated patients with haemophilia were infected with either HIV or hepatitis C before it became possible to remove those viruses from clotting factors made from human plasma.

As a result, around 4,000 to 5,000 haemophiliacs are estimated to be infected with hepatitis C and around 500 are still living with HIV. Most of those with HIV are also infected with hepatitis C. This co-infection may accelerate the clinical course of both disorders as well as making the haemophilia more difficult to manage. They therefore face considerable medical and psychological problems over and above those faced ordinarily by people with haemophilia.

The Government have enormous sympathy for haemophiliacs in this situation. It is therefore essential that the National Health Service is properly geared up to delivering the full range of clinical and support services needed by people with haemophilia and treatment-acquired infections. These include routine and emergency medical treatments, drug therapies, physiotherapy, counselling, genetic services and specialised services for HIV and hepatitis.

I shall say more about these broader issues in a moment, but first I want to respond to the many points made by noble Lords. I begin with the call on the Government to provide financial assistance for people with haemophilia and hepatitis C and their dependants. As Members of this House are well aware, we met the Haemophilia Society in 1997 and listened to its arguments for a special payment scheme for people with haemophilia and hepatitis C similar to that in place for HIV. After long and careful consideration, we came to the same conclusion reached by the previous government; that a special payment scheme should not be established. Succeeding Ministers have reviewed that decision and have reached the same conclusion. It has also been debated on numerous occasions in both Houses. It is not a view we have come to lightly. I can assure noble Lords that every one of my colleagues who has looked at this issue and met individuals directly affected by this tragedy has found this a most difficult position to arrive at.

The Government have also considered the suggestion that we might provide a limited special payment scheme or hardship fund. However, as we do not make payments to other groups or individuals inadvertently harmed by the National Health Service, the same arguments apply. We believe that the financial needs of people whose condition results from inadvertent harm should be met through the benefits system. I know that the Haemophilia Society does excellent work in ensuring that people with haemophilia are made more fully aware of their benefit entitlements.

It has been the policy of successive governments that compensation or other financial help to patients is paid only when the National Health Service or individuals working in it are at fault. The underlying principles are clear cut and independently established under common law. They apply to personal injury cases in general, not just those arising from health care. There have been no new developments to change this long-standing policy.

We are currently assessing the implications of the recent decision in the High Court (raised by noble Lords) to award damages to 114 people infected with hepatitis C through blood transfusion before the introduction of screening for the virus in September 1991. The case was brought under the Consumer Protection Act 1987 which introduced strict liability for products judged to be defective. However, the judgment does not impact on the question of compensation for haemophiliacs with hepatitis C who were infected before the Act came into force in March 1988.

The Government have decided not to seek leave to appeal against the judgment. Although an appeal would have provided an opportunity to seek clarification on some aspects of the judgment that may have a bearing on the future liability of the National Health Service bodies, the Government did not wish to subject the claimants to a further period of uncertainty while an appeal was under way.

As I mentioned, we are now focusing on the implications of the judgment, which will take time to consider. However, we have no plans for the introduction of a no-fault compensation scheme. Such a scheme would have far-reaching policy and financial implications which would need to be explored very carefully.

During the course of our debate, comparisons have been made between the decision not to offer special payments to haemophiliacs with hepatitis C and the special payments established in the late 1980s for haemophiliacs with HIV and the ex gratia payments we are making to people with variant CJD and their families. However, there are significant and real differences between these situations.

In the case of HIV, we need to think back to the circumstances of the late 1980s when HIV was having a vast and dramatic impact. It was a source of fear and a stigma for all those who became infected with the virus. There was wide-scale public reaction. HIV then was a new sexually transmitted infection which was rapidly fatal. There was no treatment and, at that time, death from AIDS-related diseases was considered inevitable.

It was in that context that special payments were introduced and the Macfarlane Trust was established. We see this as a reflection of those truly exceptional circumstances and the very poor prognosis at that time for people with haemophilia who became infected with HIV.

Questions have also been asked about the parallels between those infected with hepatitis C and those with variant CJD. However, while the Government have agreed ex gratia payments for victims of variant CJD in the wake of the Phillips inquiry, the circumstances and background to this situation are truly exceptional. It therefore does not change our long-standing policy on compensation for injuries caused by the National Health Service, which I firmly believe is the right one.

The noble Lord, Lord Astor, raised the issue of comprehensive care centres. There are 18 centres throughout England and smaller haemophilia centres in each National Health Service region in England providing care and counselling to haemophiliacs.

Noble Lords have called for a public inquiry. I can understand that people infected with hepatitis C want to know how it happened and why it could not have been prevented. But the fact is that this was a global problem linked to developing science and technology. It was not confined to the UK or linked to some local breakdown in blood product development. No public inquiry is likely to provide a satisfactory answer. Our aim now is to move forward to enable people with haemophilia and hepatitis C to get on with their lives and to look constructively at how we can improve their health and well-being here and now.

Several points have been made about the provision of recombinant clotting factors. Recombinant clotting factors are commercially produced through genetic engineering outside the human body. They are not yet entirely free from human products, as they contain small amounts of human albumin as a stabiliser. The Haemophilia Society, the UK Haemophilia Centre Doctors Organisation and others have petitioned us to make recombinant Factor 8 and Factor 9 the treatment of choice for people with haemophilia. That is largely on the grounds that recombinant products are regarded as free from the risk of transmission of as yet unknown viruses and free from the theoretical risk of variant CJD.

There is a serious world-wide shortage of recombinant clotting factors. That has been exacerbated recently by the temporary removal from the market of a Factor 8 product used extensively in the UK. The Government have been working closely with the UK Haemophilia Centre Doctors Organisation and with suppliers of clotting factors to manage the situation in a way that best meets the needs of haemophilia patients. However, that illustrates the very real problems faced by the UK and other countries in securing sufficient and sustainable supplies of these products.

That is one of the factors uppermost in our minds in considering the call to place all adult haemophilia patients in England on recombinant clotting factors. We have not yet come to the end of our deliberations on the issue, so I am unable today to give noble Lords the assurances they are seeking. The Government already require National Health Service trusts to provide recombinant Factor 8 and 9 for all new haemophilia patients and children under 16. Other patients can also receive recombinant if it is prescribed for them, although there is no requirement on trusts to do so. Over 50 per cent of the clotting factors prescribed in the National Health Service in England are currently recombinant. However, the fact remains that there is insufficient recombinant clotting factor available now and in the immediate future to give it to every patient who would like to have it.

However, I can assure the House that the plasma derived clotting factors that patients are receiving are just as effective as recombinant products. Since the introduction of viral inactivation they have had an excellent safety record. They are made from non-UK plasma to reduce the theoretical risk of variant CJD and are subject to the same rigorous assessment for safety, quality and efficacy as all other medicines. Manufacturers of blood products, such as the National Health Service-owned Bio Products Laboratory, are also required to meet very stringent requirements of good manufacturing practice regulated by the Medicines Control Agency.

Looking to the future, the Government want haemophiliacs with hepatitis C to receive the best treatment and care we can provide; and that is where I hope we can begin to focus our energies.

**Lord Morris of Manchester:** My Lords, I am grateful to my noble friend for giving way. The noble Lord, Lord Astor of Haver, raised a specific case. In Manchester's haemophilia treatment centre, patients from North Wales have to be treated more beneficially than local people because of a decision by the Welsh Assembly. What possible defence can be offered for treating people in Manchester differently from people from North Wales who are visiting the North-West of England to attend the treatment centre? They have to be prescribed recombinant treatment as of right and regardless of age and, therefore, are treated more beneficially than Manchester patients. Is it not possible now to say that such discrimination cannot continue?

**Lord Burlison:** My Lords, the noble Lord, Lord Astor, raised the issue in relation to recombinant factors and treatment. I tried to set out the difficulties surrounding that issue at the moment. The Government are considering the issue. Indeed, when they are in a position to do so, they will make a decision. If the noble Lord is not happy with that, I am ready to write to him.

The noble Lord, Lord Astor, raised the issue of consistency of treatment. There is evidence that greater consistency is needed across the country in the delivery of clinical care for haemophilia patients. The professional groups with an interest in haemophilia have recommended the development of a set of minimum standards for service delivery. That should be a very effective way of helping to standardise all aspects of haemophilia services in the longer term and get rid

of any unacceptable variations in care. With that in mind, the Haemophilia Alliance, which includes the Haemophilia Society and the UK Haemophilia Centre Doctors Organisation, has developed a national service specification. The specification outlines the key components of a high quality haemophilia service, whether that is provided in the larger comprehensive care centres or the smaller haemophilia centres. That is currently out for consultation. The Department of Health will be submitting its comments shortly.

The Government recognise the importance of hepatitis C as a public health issue and the need to ensure that effective prevention, testing and treatment services are in place. It is essential that activities to tackle hepatitis C are developed in a strategic and co-ordinated manner. I believe that we are already doing that, but we wish to develop and strengthen our efforts.

As noble Lords will be aware, the Government have recently announced the establishment of a multi-disciplinary steering group to assist in developing a strategic approach to hepatitis C. The steering group, which is chaired by Professor Howard Thomas of Imperial College School of Medicine, will bring together issues relating to prevention, control and treatment. It will produce a document by the end of this calendar year for consultation with the National Health Service, professional bodies and voluntary and community sector organisations.

In 1999 we asked NICE to assess the interferon/ribavirin combination therapy as a matter of urgency. NICE's guidance was published last autumn and provided clear and authoritative advice for clinicians and healthcare providers. Combination therapy is recommended as the treatment of first choice for moderate to severe hepatitis C in previously untreated patients and patients treated with interferon monotherapy who responded but have relapsed. The treatment should make a significant improvement to the prognosis for many people with hepatitis C.

Several other therapeutic agents which also show great promise are in development. Other treatments are being researched, such as different combinations of drugs. The next few years are likely to see significant developments and improvements in the treatments available.

As I have outlined, there is much that we can do and are doing through improved treatments and services to help people with haemophilia. We shall continue to work with all those involved in haemophilia care to improve the services and support available to haemophiliacs with hepatitis C.

**Lord Ackner:** My Lords, before the noble Lord sits down, I wonder whether he can help me on one point. I understand fully the principle to which the Government have adhered; namely, that compensation is not paid in a situation such as this, where negligence cannot be established. What would assist me would be to understand how the position of haemophiliacs differs from that of victims of criminal injuries; that is, persons who have been injured by criminal activity. Millions of pounds have been spent and continue to be spent, but there is no question of any negligence or vicarious liability. Can the noble Lord explain how to differentiate one from the other?

**Lord Burlison:** My Lords, I understand the noble and learned Lord's question, but I do not think that I can assist him. This is an area I would be quite loath to go into. I shall write to the noble and learned Lord on the matter.

#### **National Blood Authority**

**29<sup>th</sup> March 2001**

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

What consideration they have now been able to give to the judgment of Mr Justice Burton in the High Court on 26th March concerning contaminated blood supplied by the National Blood Authority.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):** My Lords, the judgment is long and complex and we are unable to offer any comment until we have had the opportunity to assess it carefully.

**Lord Morris of Manchester:** My Lords, I am grateful to my noble friend; but would he at least accept Mr Justice Burton's core finding that the supplier of blood to NHS patients has a legal duty to supply clean blood? Is he aware that, of 4,800 people with haemophilia who have been infected with hepatitis C by contaminated NHS blood and blood products, 114 have now died of liver disease and that of 1,200 infected with HIV, 900 have since died of AIDS? Would it not thus be cruelly unfair to deny a stricken haemophilia community even the benefit of the High Court's core finding? Is it not time now to let right be done?

**Lord Hunt of Kings Heath:** My Lords, I agree with my noble friend that the community in relation to whom he addresses his remarks has suffered very much. We feel a great deal of sympathy for those people. The issues are distinct. Prior to

1985, the technology to make blood products free from hepatitis C in sufficient quantities to treat all haemophiliacs in the UK was simply not possible. Once it was, the NHS introduced it. Government policy in this case is that compensation or other financial help is not payable. That decision was reached by the previous government. The judgment given on Monday does not affect that decision as the Consumer Protection Act did not come into force until March 1988.

**Lord Clement-Jones:** My Lords, the Minister mentioned that it was too early for the department to have made an assessment. However, his officials seem to be warning journalists about the implications. The Independent stated:

"Department of Health officials privately warned that the implications of the 173-page judgment were that the NHS could face claims for hundreds of millions of pounds in compensation if the same reasoning was applied in other cases where patients suffered unpreventable injury".

Despite the timing, is that not so in the case of haemophiliacs who have been infected with hepatitis C? Would not it be far better if the department finally came up with a compensation scheme after all these years? That would save the cost of litigation and the eventual damages to be paid.

**Lord Hunt of Kings Heath:** No, my Lords, there are two distinct issues. The judgment is very long. It was published on Monday of this week. It is important that we have enough time to consider the full implications. When we have done so we shall give our views and an assessment of the implications for the NHS as a whole.

As regards compensation, I can only repeat what I said earlier. We have reviewed the decision taken by the previous government not to offer financial assistance to haemophiliacs infected with hepatitis C through blood products. We met the Haemophilia Society and spent a good deal of time considering the evidence it presented. The decision was not easy. However, the decision was that we could not make an exception in this case to the general rule that compensation or financial help is only given when the NHS or individuals working in it are at fault.

**Lord Peston:** My Lords, does not my noble friend find his own Answer somewhat surprising if one applies to it even the most elementary ethical principles? The logic of his position seems to be that we could not know that we were to produce this catastrophe, and because we did not know, we cannot compensate people for the consequences of our actions. I well understand the technicalities of my noble friend's Answer. However, I do not understand the ethical position now adopted by the Government. People have died as a result of these actions and others are in danger. I should have thought--on all sorts of grounds in which once, at least, our party used to believe--that compensation is exactly the right path to take.

**Lord Hunt of Kings Heath:** My Lords, the position is clear and has been stated policy by successive governments. It is that, in general, compensation is paid only where legal liability can be established. Compensation is therefore paid when it can be shown that a duty of care is owed by the NHS body; that there has been negligence; that there has been harm; and that the harm was caused by the negligence.

Of course the Government have every sympathy with the people who were so affected, but I do not believe that sympathy can lead us to change that general principle.

**Baroness Gardner of Parkes:** My Lords, will the Minister confirm that this case was the first to be brought under consumer legislation and that it therefore opens up many new concerns, particularly in the part of the NHS? Can that consumer legislation apply in the case of anyone who dies as a result of a blood transfusion, even a life-saving blood transfusion which subsequently develops into a disease such as BSE? Furthermore, is it correct that the Government are appealing against the decision?

**Lord Hunt of Kings Heath:** My Lords, the question of appeal will be considered when we have received full advice from the lawyers involved. I repeat that this is an extensive judgment, 320 pages long. Potentially, it has wider implications for the NHS and we need to give careful thought to it before deciding what further action might be taken.

As regards the NHS, this is the first judgment under the Consumer Protection Act 1987. The judge's main findings were that the public are entitled to expect that the blood they receive will be 100 per cent safe. The judge's conclusion was that the knowledge of the medical profession is not relevant in determining the legitimate expectation of the public, nor is it a relevant circumstance that that effect could not have been avoided. The judge concluded that once the risk is known about, the product is defective even if the risk could not be identified in the product. As noble Lords will realise, we must give careful consideration to those implications.

**Lord Walton of Detchant:** My Lords, some 10 years ago there were extensive discussions in this House about the possible introduction of a no-fault compensation scheme along the lines of those which exist in New Zealand and certain

other countries. At the time, the government of the day said that they did not want to introduce such a scheme but that they would give the matter further consideration.

That proposal has fallen by the wayside. When these blood products were produced no one could have known that they were likely to transmit these viral infections. Hence, in my view, it would be impossible to come to a decision that the Government were negligent. However, is it not time that the question of no-fault compensation should be reconsidered?

**Lord Hunt of Kings Heath:** My Lords, I assure the noble Lord that we are reviewing a range of issues surrounding compensation, in particular the problem of litigation in the NHS and the best way to tackle that, including the process used to deal with clinical negligence claims and how we can improve it. We shall continue that work in considering how best to take the matter forward.

In the context of the NHS, no-fault compensation schemes offer some advantages, but there are disadvantages, too. Once one examines the position in detail, one sees that it is not easy to reach a simple conclusion on that matter.

**The Countess of Mar:** My Lords, since the Government came into power, what has been the cost of litigation within the NHS? Are those costs balanced against compensation which might be paid to individuals who are aggrieved?

**Lord Hunt of Kings Heath:** My Lords, I shall give clinical negligence payments over the past five years. In 1994-95 they were £160 million; 1995-96 they were £173 million; in 1996-97 they were £235 million; in 1997-98 they were £144 million; and in 1998-99 they were £221 million. Those are substantial payments and anyone concerned with the well being of the NHS must be worried that such a degree of resources is being spent in negligence payments.

Two issues are involved. The first is the question of whether we can improve the whole clinical negligence process. The second is to improve our procedures within hospitals and other healthcare services so that we are less vulnerable to claims in future.

**Lord Colwyn:** My Lords, will the Minister try to persuade his department to publicise the fact that it is beneficial to health, particularly of men, to give blood on a regular basis? Furthermore, are there any age limits on blood donors?

**Lord Hunt of Kings Heath:** My Lords, I believe that there are age limits but we want to encourage as many people as possible within those limits to give blood. It would be fair to say that, under new leadership in the National Blood Service, during the past two or three years the stocks have blood have increased enormously. I echo the noble Lord's remark that we must encourage more people to give generously in that respect.

#### **Haemophilia Treatment**

**26<sup>th</sup> March 2001**

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

What new help they are considering for people with **haemophilia** who have been infected with life-threatening illnesses by contaminated National Health Service blood products.

**Lord Burlison:** My Lords, in England all new **haemophilia** patients and children under 16 are treated with recombinant clotting factors. Scotland, Wales and Northern Ireland provide, or are in the process of providing, recombinant clotting factors for all **haemophilia** patients. The Government are currently considering whether all adult **haemophilia** patients in England should also be treated with recombinant clotting factors when sufficient supplies are available.

**Lord Morris of Manchester:** My Lords, I am grateful to my noble friend. As he knows, this Question is about what doctors of the highest distinction have described as "the worst treatment disaster in the history of the NHS". Is my noble friend also aware of the High Court's landmark ruling today that the National Blood Authority was negligent in supplying blood contaminated with hepatitis C and has awarded significant compensation? Will the unmistakable logic of that ruling now be applied to **haemophilia** patients given hepatitis C by contaminated NHS blood products?

Moreover, is it not cruelly unfair to deny safer recombinant blood products to English patients with **haemophilia** aged over 16 when there is now no such restriction in Scotland and Wales? Does not this take the "N" out of NHS?

**Lord Burlison:** My Lords, first, I pay tribute to my noble friend's work for the cause of those throughout the United Kingdom suffering from **haemophilia**. I congratulate him on his role as president of the **Haemophilia Society**. I am sure that it could have no finer advocate. The case referred to was brought by a number of claimants infected by hepatitis C through blood transfusions against the National Blood Authority under the consumer protection legislation of 1988. The

judgment is about 350 pages long and very detailed. It would be inappropriate for me to comment further until the details of the judgment have been fully assessed.

My noble friend referred to the availability of recombinant treatment in Scotland, Wales and Northern Ireland. Recombinant treatment is currently available to new patients, those under 16 years of age, and patients outside those categories where prescribed. Not all haemophiliacs may want recombinant treatment. However, the Government are considering whether all haemophiliacs should be treated with recombinant clotting factors. We realise that there is a shortage and the Government are looking for additional suppliers.

**Lord Clement-Jones:** My Lords, haemophiliacs have little confidence in conventional blood products. What are the Government doing to tackle the serious shortage of the recombinant factor? When will the Government consider whether haemophiliacs in England above the age of 16 will be able to have recombinant factors?

**Lord Burlison:** My Lords, there is no evidence that recombinant factors are safer than plasma-based products. However, discussions on recombinant factors are ongoing. The Government are currently considering whether all adult haemophiliacs in England should be treated with the recombinant factor. It is an ongoing process. As soon as the Government have arrived at a decision they will inform those concerned.

**Baroness Gardner of Parkes:** My Lords, the Minister states that it is an ongoing process. I raised the matter in 1997 so it has been ongoing for a long time. What does the noble Lord mean when he states that there is no evidence that the recombinant factor is safer? Is it not correct that the recombinant factor is artificially produced and, therefore, cannot carry human blood contamination? How many haemophiliacs have died from HIV/AIDS and how many are currently diagnosed as having the condition?

**Lord Burlison:** My Lords, the noble Baroness poses a number of issues. I cannot respond in the detail that she may seek. The noble Baroness raised the issue as far back as 1997. Indeed, it was raised before that period. It has been a lengthy process. Like their predecessors, the Government decided that patients under 16—their parents were obviously worried about them—would have the recombinant factors afforded to them. Where it is prescribed, the treatment will be given. The Government are still considering whether to extend supply to all haemophiliacs in Britain. As soon as a decision is made, I am sure that the noble Baroness and this House will be informed.

**Lord Walton of Detchant:** My Lords, does the Minister agree that unlike earlier preparations such as Hemophil, which were derived from human blood products, the recombinant preparation is not made from human blood but is based upon genetically-produced factor VIII? Hence, it cannot in any circumstances transmit viral infection to those who receive it. In view of the Government's commitment to reducing the lottery of postcode prescribing in the National Health Service, would it not be appropriate rapidly to make this preparation available to all patients with haemophilia in England, of whatever age?

**Lord Burlison:** My Lords, I do not question the noble Lord's interpretation of the recombinant factors. Indeed, I agree with what he said in that respect.

Prescribing recombinant factor VIII or IX for everyone is under consideration at present. However, some may not wish to have treatment with the recombinant factor. Supplies are not adequate at present to prescribe the recombinant factor for everyone concerned. The Government seek to ensure that resources are made available. As matters develop, they will be able to make a decision on the issue.

**The Countess of Mar:** My Lords, the Minister gave a full answer to part of the Question asked by the noble Lord, Lord Morris, but he said nothing about those who have been infected with life-threatening illnesses. What are the Government doing for those who have been infected with hepatitis C or HIV/AIDS? Are they considering compensation for such people, or at least special provision for their current needs?

**Lord Burlison:** My Lords, the policy on compensation has remained the same for many years. Compensation is paid only when National Health Service staff or those working in the NHS are at fault. Before 1985 it was not possible to make blood products free from hepatitis C in sufficient quantities to treat all haemophiliacs in Britain. There are no reported cases of classical or variant CJD transmitted by blood or blood products. All the evidence suggests that classical CJD is not spread by blood products. It is too soon to detect any potential transmission of variant CJD by that route, although the possibility cannot be ruled out entirely.

**Earl Howe:** My Lords, I should like to pick up on a point made by the noble Lord, Lord Clement-Jones, which I am not sure that the Minister covered fully. What are the Government doing to address the serious shortage of recombinant products that has arisen in recent days?

**Lord Burlison:** My Lords, there is a shortage and the Government are seeking additional suppliers. I hope that there will be developments in that respect.

## Hepatitis C

18<sup>th</sup> December 2000

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

What recent new help they have given to those who were infected with hepatitis C by contaminated National Health Service blood products and the dependants of those who have since died in consequence of their infection.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):** My Lords, on 31st October the National Institute for Clinical Excellence recommended that patients suffering from moderate or severe hepatitis C should be given the combination therapy, Alpha Interferon with Ribavarin. My department will also make funding available to the Haemophilia Society over three years to help improve counselling for people with haemophilia infected with hepatitis C.

**Lord Morris of Manchester:** My Lords, I am grateful to my noble friend for his reply. Is he aware that contaminated NHS blood products have now taken the lives of 1,000 people with haemophilia in what my noble friend Lord Winston has called the worst treatment disaster in the history of the NHS? Should there not be a public inquiry into the disaster, as the Haemophilia Society requests? Again, why cannot safer recombinant treatment be available to all adults and children in England as it is already in Scotland, Wales and Northern Ireland? And why cannot people infected with hepatitis C be given the same "no fault" financial help as people with HIV?

**Lord Hunt of Kings Heath:** My Lords, I pay tribute to my noble friend as president of the Haemophilia Society for bringing this serious concern of what has happened to many people to your Lordships' attention. The Government reviewed the decision taken by the previous government not to offer financial assistance to haemophiliacs infected with hepatitis C through blood products. Our decision was that an exception could not be made to the general rule that compensation or financial help is only given when the NHS or individuals working in it have been at fault.

There is no evidence that recombinant synthetic factor 8 and factor 9 are more effective or safe than plasma-based products. However, I understand the anxieties expressed by the haemophilia community. That is why we instructed health authorities to provide recombinant products to new patients and children under 16 with haemophilia. I understand the point made by my noble friend. I shall be meeting with the Manor House Group later today and with the Haemophilia Society in the new year. I am sure that this will be one of the issues we discuss.

**Lord Clement-Jones:** My Lords, in a debate in March the Minister claimed that the department had no legal liability towards haemophiliac sufferers because blood testing was introduced as soon as technology was available. Recently, there have been reports in the Scotsman that regional directors of blood transfusion centres met in 1986 and decided not to go ahead with hepatitis C screening because of lack of time and resources. Does not that alter the complexion on the matter? Is it not high time the department altered its view and gave financial compensation to those sufferers?

**Lord Hunt of Kings Heath:** My Lords, I have not seen the report in the Scotsman. I shall be prepared to look at it if the noble Lord, Lord Clement-Jones, will pass it to me. But it is not my understanding that there is any move from the position that the English NHS was not shown to be at fault. As the noble Lord will understand, an inquiry by the Scottish Administration took place recently. However, that was not a general inquiry into hepatitis C and blood products. It looked specifically into whether or not Scottish haemophilia patients were exposed to the risks of hepatitis C for longer than they should have been, given the fact that Scotland developed successful heat treatment later than England. Scottish Ministers considered a report in that regard and concluded that there was no evidence that the relevant authorities did other than their best for patients.

**Baroness Gardner of Parkes:** My Lords, I ask the Minister to think again about his answer when he said that there was no evidence that recombinant was safer than normal blood products. I thought it had been clearly established that all hepatitis C infections came about because of the product being derived from normal blood. Is it not a fact that one of the big stumbling blocks has been VAT on the chemical product? As we have been told repeatedly that the Chancellor of the Exchequer would investigate that matter, can the Minister say whether he has done so because such a move could save many people from contracting hepatitis C?

**Lord Hunt of Kings Heath:** My Lords, VAT issues are always under discussion, but I have seen no evidence that recombinant factors are more effective or safer than plasma-based products. That is the advice I have received. However, as I have said, I understand the concerns expressed by the haemophilia community and will be discussing them with the Manor House Group and the Haemophilia Society.

**Earl Russell:** My Lords, may I thank the Minister for small mercies? However, is he aware that the failure to respond to the question my noble friend Lord Clement-Jones asked about compensation discredits government and therefore diminishes the standard of our politics?

**Lord Hunt of Kings Heath:** My Lords, I did not fail to respond to the noble Lord but I reiterated the Government's decision in the light of the careful review which they undertook when they came to office. These are difficult decisions but nevertheless one was arrived at—and it was the appropriate decision.

#### Hepatitis C

1<sup>st</sup> November 2000

**Earl Howe** rose to ask Her Majesty's Government what plans they have to improve the care and treatment of patients with hepatitis C.

The noble Earl said: My Lords, this Question has been triggered by a series of briefings given to me recently by the British Liver Trust. Its work, together with some academic research to which I have had private access, leads me to conclude that there is a great deal to be done before the service provided by the NHS to patients with hepatitis C, or to those who are suspected of having it, can be considered in any way satisfactory.

I begin with some factual background. Hepatitis C is what might be termed a "new" disease. As a virus it was separately identified only in 1989, although it is known to have existed in various parts of the world long before that. The World Health Organisation estimates that more than 170 million people worldwide may be infected with it. In Asia and parts of Africa, and especially in Egypt, its prevalence is 10 per cent or more. In the UK the best and most recent estimates are that it affects approximately 0.7 per cent of the population, equal to perhaps 400,000 people. That figure is only a rough guess based on extrapolations. The true figure could be lower or, more likely, a great deal higher. I shall return to that issue in a moment.

The hepatitis C virus, or HCV, is a blood-borne infection. There are thought to be at least six strains of the virus, each with sub-strains numbering about 40. Over the course of time these strains may change spontaneously. It is partly for this reason that to date no vaccine for hepatitis C has been developed. It is commonly agreed that the largest single transmission route is through intravenous drug misuse. There are, however, many others, including transfusions of contaminated blood before the introduction of screening procedures and maternal transmission in pregnancy. HCV, therefore, cuts right across the social spectrum. In prisons where the incidence of HCV is especially high, transmission occurs not only through the re-use of needles among drug-users but also from the sharing of items such as razors and toothbrushes which may draw blood.

The incubation period of the disease is long. A large percentage of people who develop hepatitis C today are in their 40s and will probably have contracted it 20 or more years ago. It is this feature of HCV which is particularly significant in terms of healthcare planning. Even if all the routes of transmission were somehow to be closed off tomorrow, we would still face the prospect of large numbers of cases emerging over the next 10 to 20 years.

What implications does this have for the NHS? The good news, such as it is, is that hepatitis C is by no means always fatal. Indeed in 20 per cent of cases it disappears spontaneously. However, in the other 80 per cent of cases, the vast majority of those infected will go on to develop a long-term chronic illness. Some 20 per cent will contract cirrhosis of the liver, and of those half will develop liver cancer. Even among those less severely affected the symptoms of the disease can be debilitating—fatigue, depression, lethargy and a resultant poor quality of life are common. If, as some specialists predict, we can expect to see many hundreds of thousands of people needing treatment for hepatitis C over the next decade, the costs to the National Health Service are likely to be significant.

Combination therapy, involving Interferon and Ribavirin, costs some £9,600 per annum per patient. Although it is able to cure up to 40 per cent of patients, the majority of health authorities either do not provide it at all or provide it on a limited and inadequate scale. Indeed, in a survey conducted by the British Liver Trust in 1998, it was found that only a fifth of health authorities had any sort of strategy for tackling HCV, and fewer than one third had a budget for treating it.

The postcode lottery is therefore alive and kicking with hepatitis C. In part, that is a simple reflection of inadequate funding. It is also explained by uncertainty among GPs and health authorities about the cost-effectiveness of combination therapy. That uncertainty should now be banished in the light of the guidance published this week by NICE. The NICE guidance, though effectively only re-stating the established evidence about the clinical effectiveness of combination treatment, is nevertheless very welcome.

What are at stake, of course, are not simply the direct benefits that combination therapy can bring to patients. Timely drug treatment reduces the long-term costs of care. In particular, it can reduce the need for liver transplants, which can cost up to £50,000 per patient, excluding follow-up medication. It also mitigates the high cost of providing care for patients who

develop advanced liver disease and associated complications. It is disappointing that these issues appear not to have been examined by NICE as part of their evaluation.

The idea, however, that the NICE guidance will somehow solve the postcode lottery is, I fear, over-optimistic. Health authorities will still need to prioritise funding to meet the cost of treatment. Those costs have been estimated by NICE at £18 million per annum initially. That figure excludes the associated costs for pathology, virology, radiology and specialist nursing. The verdict of every reputable HCV specialist is that spending money early will save a great deal more money later. Yet we have to ask what incentive a health authority has to invest those very considerable sums. One deterrent, incidentally, is that the costs of liver transplants, unlike combination treatment, are funded centrally.

On this side of the House we believe that the barrier to funding relatively expensive drug therapies such as Interferon alpha and Ribavirin could be eliminated by the creation of a central funding mechanism for such exceptional medicines, quite separate from health authority budgets. But if that is not to happen, then the very least that is needed is clear guidance from government to health authorities to make the therapy widely available.

But therapy is only one aspect of the problem. There is a woeful lack of proper facilities in many areas to test and counsel HCV patients. There is no common protocol to which health authorities work in looking after and managing such patients, both before and after testing. One important improvement, mentioned by NICE, would be the wider availability of confidential testing facilities, of the kind that currently exist for HIV. It is thought that many people are deterred from seeking a test for HCV because it will feature on their medical record. That in turn will stigmatise them in their prospects for employment, life insurance and a mortgage. It will also have an effect on personal relationships. As a result it is likely that many people whose condition could otherwise be arrested are not even being diagnosed.

Just as there is no uniform pattern throughout the country in the provision of testing facilities, so too there are very varied procedures followed for the counselling of patients. The way in which patients are presented with their test results is often insensitive and ill-thought through in the extreme. A great many receive no advance preparation for what they are about to hear and no advice about it afterwards. When so much is at stake, that cannot be a satisfactory way of proceeding. As NICE says explicitly in paragraph 5.21:

"Confidential HCV testing and counselling should be made available whether or not treatment is initiated."

The other area crying out for funding is research. There is much about HCV that remains unknown. Some aspects of the pathogenesis of HCV are still hidden. The precise mechanisms by which HCV causes liver cancer have not been identified. We still need a simple, cost-effective and reliable diagnostic assay test, both for the initial detection of HCV and for monitoring the disease as it progresses. There are still no firm data on the susceptibility of HCV to disinfecting agents, which is important bearing in mind that the virus, unlike HIV for example, can survive many hours outside the body. Perhaps the Minister can tell the House what research is currently being conducted in any of those areas.

It is all too easy to stand in your Lordships' House and sound alarmist. I never have any wish to do that. Nevertheless, when medical experts tell us that, "We are poised on the brink of an epidemic, which could have far wider ranging implications than AIDS", we have a duty to pay close attention. Those were the recent words of Dr William Rosenberg, senior lecturer in medicine and consultant physician at Southampton General Hospital and the University of Southampton.

There are other experts who predict that in two or three years' time, hepatitis C will outstrip AIDS as the most common cause of death in early and mid-life. The NHS needs not just guidance from NICE but a co-ordinated strategy. Variations in facilities and inappropriate management procedures need to be ironed out.

To that end, I would welcome the Minister's comments on the merits of trying to devise a national protocol for the management of HCV, building on the NICE guidance; perhaps in the first instance by adopting the guidelines issued by the European Association for the Study of the Liver. A linked, but separate, strategy needs to be adopted in the Prison Service. Overarching all of that, there has to be a clear policy on educating the public about the risks of HCV and about prevention.

All this amounts to a great deal. I make no apology for listing what needs to be done, because the gaps in the provision of services are currently wide. But I hope, at the very least, that the Minister will say that he shares my perception of this issue as one of the most pressing and least well-resourced of any now facing the National Health Service. I dare to hope, too, that this debate will serve to add impetus to the Government's efforts to iron out those inequalities in healthcare provision on which the Minister and his colleagues have rightly laid such emphasis.

**Baroness Masham of Ilton:** My Lords, I am grateful to the noble Earl, Lord Howe, for giving your Lordships the opportunity of discussing the hepatitis C virus tonight, and for the noble Earl's most informative speech.

When I said to one of the Doorkeepers last night that we would be discussing HCV tonight, he said, "I know A and B, but what is C?" Does the Minister think that there should be more health education on this subject? Should not the public be made more aware of this worldwide virus? Prevention is better than cure, as cure seems difficult.

There are many injecting drug addicts past and present who are HCV positive. People who go in for body piercing and tattooing can also be at risk. All health workers involved with taking blood or working with needles are at risk of needle stick infection. HCV can lie in the body for up to 30 years and therefore positive people can be at risk of infecting others. Can the Minister tell the House what development and progress there is on a vaccine for HCV?

When I broke my back and had a severe internal haemorrhage, I had several blood transfusions, for which I was very grateful as they saved my life. Years later I had to have blood transfusions again, and the third time it was discovered that my blood group had changed from negative to positive. I can assure your Lordships that I was very uneasy when that happened.

The last transfusion I had was around the time when HIV presented in the UK and hepatitis C was being recognised. Some years later, because I had had blood, I requested a blood test for HCV. It was not an easy process. The nurse involved asked me what I would do if I was positive. I told her, "At least I would know". I hope that the process of testing and counselling has improved.

From what I have heard there seems to be no national strategy for dealing with hepatitis C and no national guidelines on the management and treatment of those infected. This complete lack of planning of HCV services throughout the UK results in very variable standards of management and care after diagnosis for any patient with hepatitis C. In some areas of the UK patients have to wait months or years with hepatitis C to see a hepatologist or HCV specialist and there are very few counselling and support services.

Hepatitis C is difficult to treat. Interferon and Ribavirin combination therapy was licensed last year and has been shown to clear the virus in about 30 per cent of cases. It is a highly unpleasant treatment to take, however, and the decision to start therapy seems never an easy one. Currently, many health authorities are denying the treatment to people with HCV on funding grounds, thus removing any hope of a cure.

With so many difficult problems facing our National Health Service, particularly the shortage of skilled staff, can the Minister say how the National Blood Service is coping? Has it enough skilled technicians and doctors to ensure that blood and blood products are safe from viruses such as HCV? Are the Government planning a review of the services so that the public will have confidence in this vitally important area?

I know a charming man who is a haemophiliac with HCV. He is married, working and has three young children and is taking part in trials. Can the Minister give an update on the drug trials and say which are the most successful combination therapies with as few side effects as possible? Is it a fact that the response is four times higher with Interferon Alpha with polyethylene glycol than other combinations? Does the noble Lord agree that NICE should make it clear that its conclusions may not be appropriate in the face of new therapeutic agents?

A recent European statement recommended that combination therapies should be offered to all previously untreated individuals, provided they had no contra-indications. It came from the International Consensus Conference on Hepatitis C in Paris in 1999. Does the Minister believe, like others do, that each health authority should work to a protocol in respect of the way it handles patients with HCV? Will the Government send out guidelines so that the services for patients with hepatitis C virus is a truly national one?

Tonight we are talking about patients with a serious condition resulting in haemolytic anaemia, fatigue, flu-like symptoms, bone marrow suppression and liver cancer and liver function failure. I hope that this debate will do something to help to improve their care and treatment.

**Lord Colwyn:** My Lords, my noble friend Lord Howe has raised an important issue. As he said, hepatitis C virus infection is widespread, with an estimated 3 per cent of the world population being infected. Acute infection is usually mild but chronicity develops in as many as 70 per cent of patients, of whom 20 per cent will eventually develop cirrhosis and between 1 and 4 per cent will develop hepatocellular carcinoma.

The virus has become a major issue with the media, with the focus on haemophiliacs and whether or not HCV testing in blood donors was delayed unnecessarily. But that is not the issue in this debate. Like the AIDS virus, hepatitis C virus has an imagined stigma. Some say that it is a dangerous virus on the loose, yet others say that its effects on the liver progress only very slowly and infection is asymptomatic in most patients. Many who are infected may never be detected and diagnosis is difficult as the concentration of HCV antigens in the sera of patients is so low that testing has to be undertaken in specialist referral centres.

Groups of people who are at high risk of hepatitis C infection are well defined. As I have just mentioned, haemophiliacs have an 80 per cent risk, followed by IV drug abusers at 50 to 75 per cent and haemodialysis patients at 2 to 5 per cent. There are also patients in high risk countries and patients who have multiple transfusions.

Although I am concerned that the diagnosis and treatment for patients with hepatitis C should be of the highest priority, I have a more selfish attitude in that I am equally concerned about the risk to healthcare workers who will be treating infected patients, largely without any knowledge of that infection. I declare my interest as a practising dentist working with patients who may indeed have hepatitis C. Research has shown that dentists who have not been immunised are three times more likely to acquire HBV infection than the general population and that non-immune surgeons are six times more likely to acquire the infection than is the case in the general population.

The risk to healthcare workers is low, but annually between 2 and 4 per cent of new HCV infections occur in this group. The first known case of occupational mucosal transmission of HCV involved a nurse who was splashed in the face and eyes by blood. HCV has been detected in the saliva of patients with chronic hepatitis who are undergoing dental treatment. There is a report of HCV being transmitted by saliva in a human bite. But there is little epidemiological data to suggest that saliva is a major mode of transmission. However, I am delighted to be able to say that studies show that the risk of HCV infection through the practice of dentistry generally is low.

The incidence of sero-conversion to HCV after needle stick injury exposure to HCV-infected blood ranges from 0 to 10 per cent and averages at about 2 per cent. I do not know what the average number of needle stick injuries to dentists and doctors is in this country, but I suppose that it happens to me about once a year. Sadly, rubber gloves are no protection against some of the instruments and needles that we use.

Currently, there is no vaccine for HCV and the chance of developing one is complicated by the virus's diversity and ability to mutate. Perhaps I may follow up the question of the noble Baroness, Lady Masham, and ask whether the Minister can update us on any of the latest work in this field.

The problem posed to the dental team for care of HCV patients is twofold. First, the prevention of the transmission of HCV from patients who knowingly or unknowingly are carriers of the virus to other patients, staff and dentists in the dental care setting and, secondly, the management of the patient with a degree of impaired hepatic function—however rare this may be.

The vast majority—probably all practising dentists in the UK—are aware that all patients present some potential infectious risk. Many patients are unaware of their condition and cannot be reliably identified by even the most comprehensive medical history. In view of this, a system of dental delivery is adopted for all patients which prevents the possibility of disease transmission in the dental environment. Recommendations on the prevention of cross infection are issued by the General Dental Council, the British Dental Association and the indemnity providers, of one of which I have the honour to be chairman.

I hope that the Minister will take this opportunity to reassure dentists and other healthcare workers that, with efficient cross infection control, it is most unlikely that there would be any transfer of the virus and that it is perfectly safe to treat patients with hepatitis C. This morning, I happened to see Professor Roger Williams, who asked me to stress this point. It is extremely important.

Patients who do have impaired hepatic function should be treated following consultation with their general medical practitioner as there are possibilities of a potential for post-operative bleeding and for the interaction of some commonly used drugs which are metabolised in the liver.

I am sure that the Minister will confirm the announcement by NICE, which I read in *The Times* this morning, that patients with HCV—and I presume this applies only to those with symptoms of liver damage—will be able to be treated with Ribavirin and Interferon alpha within the NHS. Sadly, there is a long list of contraindications for Interferon treatment and it is probable that those patients most likely to respond are those least likely to need immediate treatment.

A recent survey of patients with HCV in south Australia, published in the *Australian Dental Journal* this year, shows that there is a marked discrepancy between the oral health of those infected and a comparison group. I shall not go into the details of the various dental problems, but there is certainly a need for priority delivery of dental care which must incorporate a strong preventive programme and oral health education component in order to sustain health improvement. I am sure that the Minister will be able to confirm that the dental strategy has taken these priorities into account. As we passed in the corridor earlier, the Minister asked me to endorse the dental strategy. Of course I endorse it and I hope that it will deliver exactly what we are asking for this evening.

In conclusion, as a member of the Science and Technology sub-committee looking at complementary and alternative medicine and with my head full of information about homeopathics and herbal medicines, perhaps I may mention the relevance of natural medicine to patients with HCV. Despite longstanding scepticism towards the value of vitamin