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Monday, 4th June 2007

(10.00 am)

THE CHAIRMAN: Good morning everyone. So we are beginning today with the Skipton Fund, Mr Stevens and Mr Harvey. Presumably you will find it most convenient simply to make your presentation and then we can ask whatever questions --

PETER STEVENS: I will not read the paper laboriously, I will just pick out the key elements.

THE CHAIRMAN: The one thing I should say is we have not had an opportunity of reading the paper because we were given it this morning. We will not know anything which you do not actually tell us.

PETER STEVENS: The Skipton Fund is a company that was set up to administer the scheme of ex gratia payments to people who were infected with hepatitis C. The scheme was announced on 29th August 2003 by John Reid. The MacFarlane Trust was asked about a month later by the Department of Health if it would administer the scheme. Because it was a non-charitable tariff operation, it was not compatible with the charitable objectives of the MacFarlane Trust, so we were not able to do it within the Trust but the trustees of the MacFarlane Trust agreed that there were sufficient benefits to the trust in assisting the department that we agreed to put our --

THE CHAIRMAN: That would justify spending their funds.

PETER STEVENS: We certainly put our expertise and resources at the disposal of the department. The original announcement was expanded later on to indicate that it was a two-tier tariff, a payment of £20,000 to those who were infected with a subsequent payment of £25,000 to those in whom the infection had led to severe liver disease. So we established the company and entered into discussions with the department which went on for a long time. It was quite clear that there were a lot of nuts and bolts to be put together to make the initial announcement into something that would work and work out an operating mechanism for it, complicated by the fact of course that everything had to be agreed with the devolved administrations as well which led to several multiples of complexity. We got started on 5th July 2004 with a full-time administrator and a number of part-time clerical support staff.

We were told there were probably 6 to 8 thousand people who would be applying to the scheme but that was quite clearly a figure taken out of the air --

THE CHAIRMAN: That was the department's figure?

PETER STEVENS: That was the department's figure. I think there were a lot of -- they were aiming high in a number of areas to get to a figure that they felt comfortable with. When the scheme opened, the first two or three months were fairly uncomfortable because there had been quite a backlog had built up and we opened only a few weeks before the holiday season and immediately ran into staffing problems but within about two or three months we had resolved that and the operation has been running fairly smoothly ever since and with one hiccup.

It is probably easiest to go straight to statistics now. At the end of May, in other words last Thursday, we had paid 3,751 first stage applications. So that is a total payout of just a touch over £75 million and --

LORD TURNBERG: What figure was that?

PETER STEVENS: £75 million was the total we have paid out and we had paid 600 stage 2 applications which is a round sum of 15 million. So that makes a total of just over £90 million that has been paid out in nearly three years. We have rejected about 335 applications of stage one payments, about half from natural clearers, which is a phrase, if I may, I would like to return to a bit later on -- and about half on other grounds principally either lack of evidence for source of infection or complicating factors which might also have given rise to infection of which the most notable is probably intravenous drug abuse. There is an appeals panel and of those, 160, 170 who were rejected for medical grounds, about 90 have gone to appeal and the appeals panel has supported about half of those applications, upheld the rejection of about half and then there are a few that are still pending further enquiries about the appeals panel.

Looking at the year -- the last year, 2006/2007, we have been sending out new application forms at the rate of about 25 a month and paying stage 1 applications at the rate of about 20 a month. For stage 2 we have been sending out about 11 application forms a month and paying about 8. So the level of activity really now is quite low which suggests very much that the initial figures of 6 to 8 thousand people eligible is not going to be reached. It is going to be a long time before we even reach 4,000 and I would be very surprised if we ever reach 5,000.

There is obviously an expectation that the number of stage 2 payments, as a proportion of stage 1, will rise over time. At the moment it is sitting at about 18 per cent and has been sitting there for a long time. But I think the expectation is eventually it will begin to rise but may well never reach anything like 100 per cent. The point about natural clearers is possibly the main contentious point of the scheme as it is in operation. It is possible to clear the virus naturally, the hepatitis C virus naturally, and a few people do. The scheme was set up so that those who clearly had been infected but were no longer carrying the virus would be eligible for payment if during the acute phase of their infection, roughly the first six months they displayed chronic signs of infection. Those who did not display chronic signs of infection would not be eligible. Those who were infected early in the 1970s or earlier than that, were infected with a condition for which there was no test and of which there was no knowledge or definition. So determining whether or not they showed chronic signs of infection is something that people did not know anything about was slightly problematical. This applies particularly to the people with haemophilia.

Some hospitals with haemophilia departments have chosen not to discriminate between those who were infected early and whom they could not have detected chronic signs of infection and those who were infected later in some of whom they could and have put forward no applications for natural clearers, choosing to say none of you were eligible. Other hospitals have taken a different line and have put forward applications from people who were infected early. Whether or not they detected chronic signs of infection or are simply giving people the benefit of the doubt we cannot tell. We can only act on the basis of the evidence that is given to us.

THE CHAIRMAN: And you are dependent wholly or largely on the hospitals?

PETER STEVENS: We are dependent wholly on the physicians -- the physicians complete the application forms and they supply the evidence and if there are difficulties with the evidence we send the application forms back to the applicant and suggest he or she goes back to the physician and asks for further information.

So there is a problem of equity there affecting a small number but of course we do not know how many because we do not know how many people we are not hearing about.

I think probably with that, I would defer -- I would ask if you have any questions. I would say one thing that the company is operated by a board of directors, all of whom are trustees of the MacFarlane Trust as well. Its operations are governed by an agency agreement, a contract with the Department of Health. It is an agent of the Department of Health for the purpose of administering this scheme. So there are certain things that I might find it difficult to talk about, certain questions I might not be at liberty to answer freely because wearing my Skipton hat I am in an agency position.

THE CHAIRMAN: Yes. You did actually supply us with that part of the agreement related to confidentiality.

PETER STEVENS: Yes.

THE CHAIRMAN: I can understand the need for confidentiality for individuals, I have the impression that it went rather wider than that, that it is confidentiality about and of the government suppliers and the arrangements between the firm and the government. Is that right?

PETER STEVENS: It is quite a broadly drawn confidentiality agreement.

THE CHAIRMAN: I have one or two other questions which do strike me. First of all you have given us some very helpful figures. What about the present funding? Would you regard that as sufficient or is it going to cover the likely --

PETER STEVENS: The company indents the department for funds periodically in multiples of about £5 million. We try to preserve a balance of something like £1 million in our hands for two reasons. One, we do not want to delay making payments to people because we actually have not any money; we are waiting for the department to cough up. Secondly because interest earnings on the fund are largely responsible for covering the operating costs, which are pretty small.

THE CHAIRMAN: So the department does not pay in addition for operating costs?

PETER STEVENS: No, the department simply provides the fund with some money and that covers everything. On the basis that the department and the devolved administrations were originally expecting 6 to 8 thousand applicants, one might believe that somewhere there is a budget for a corresponding large sum of money. I suspect that there is not such a budget but there has been no indication that they are feeling any financial pressure from this particular operation.

THE CHAIRMAN: No.

PETER STEVENS: The staffing -- if I might say at the moment, we no longer have a full-time administrator, we have an administrator who gives some of his services to the MacFarlane Trust and some to the fund and we have a single part-time clerical assistant.

THE CHAIRMAN: Yes.

LORD TURNBERG: Can I ask about the application process? Stage 1 and stage 2, just to clarify. Is it a patient who employs in the initial instance and you send him a form and then they go to their doctor to complete it. Is that the system?

PETER STEVENS: Yes, somebody registers an interest and we make a note of the name and address.

LORD TURNBERG: That is the patient --

PETER STEVENS: That is the applicant, yes. We then send an application form. This is for stage 1 which, yes, the patient should then get filled in by his clinician. In the case of people who are already registered with the MacFarlane Trust --

LORD TURNBERG: This is for --

PETER STEVENS: Yes. The process is almost automatic. There is hardly any delay between showing an interest and becoming an eligible applicant to the fund. Somebody with haemophilia but not HIV positive -- again, it is simply a tick box exercise by the clinician saying that the person has a bleeding disorder, has received anti-bleeding -- coagulating factors of various sorts and indicating which hospital or hospital's treatment took place.

For applicants who do not have bleeding disorders, the form is more complicated because the clinician has to say when the infection was likely to have occurred, the purposes of the treatment during which the blood or blood products were provided, where this happened and to give evidence, if there are any, of any complicating factors such as medical treatment abroad, IVDA, or any other reason why the clinician thinks there may be areas of doubt.

It is in those areas that we have most of the problems of queries being generated by the forms because frequently, particularly for people who were infected a long time ago, hospital records will have been thrown away, hospitals may no longer exist, but quite remarkably a lot of records do actually come to light in GP's files if sufficient rigour is displayed in the search.

Where there is simply no evidence at all, we will tend to turn them down and suggest that the applicant might like to go to the appeals panel. But the directors do exercise a certain amount of discretion in some cases, for example, a very elderly person had a single operation in 1957 and received a blood transfusion then and there are no records, we might well say, a lady of 87 should not be kept waiting for very much longer.

But where the story is -- where there are not quite so many extenuating circumstances or something, we might say we will refer this one to the appeals panel, who will decide. The appeals panel contains a heptologist, a haematologist and is chaired by a distinguished lawyer, a lay person, a GP, and they will quite often be able to form a judgment of the nature of the medical treatment that was received and whether that is likely to have required a blood transfusion or not.

LORD TURNBERG: The stage 1/stage 2 business: stage 1 is if they have -- talking now specifically about patients with haemophilia which I suspect is a rather easier for a report to be filled in on.

PETER STEVENS: Yes.

LORD TURNBERG: Stage 1 indicates that the patient has been infected with hepatitis C. Is that the case?

PETER STEVENS: Yes.

LORD TURNBERG: And stage 2 is if they have suffered long-term chronic--

PETER STEVENS: It is then become a severe liver disease, yes.

LORD TURNBERG: Right. So a patient who was given contaminated blood some time ago who did demonstrate signs of infection but then subsequently cleared, are they eligible for a stage 1?

PETER STEVENS: They would be eligible for stage 1 if in the acute phase of infection evidence of chronic infection was present.

LORD TURNBERG: Right, okay. Can I just ask then, are there difficulties with haemophilia patients in doctors not returning the forms or saying no, I do not agree or something to that effect? It is usually -- I gather from what you said correctly, it is usually with the ones where it is uncertain about whether they had a blood transfusion and they did not have the infection.

PETER STEVENS: As far as we are aware, there is no difficulty with haemophilia patients. We are surprised that we are still receiving forms from people with haemophilia. We would have thought that they would be have been in a position to get their applications in fairly quickly but we suspect this comes from people with very mild haemophilia who do not often go to see their haemophilia centres and only occasionally have to make reference to the doctor and if their condition is then discovered. People without bleeding disorders -- I think there are probably many people still recovering who are not even aware they have hepatitis C but as I say, no as many as to reach the figure of eight thousand.

LORD TURNBERG: Finally just for completeness, the sum of money that is awarded and how that is arrived at, do you want to just go through that?

PETER STEVENS: The 20 and £25,000?

LORD TURNBERG: Yes.

PETER STEVENS: Those were laid down by the Secretary of State fairly early on in the process.

LORD TURNBERG: In 2003?

PETER STEVENS: In 2003 we had no influence on that at all.

THE CHAIRMAN: Have you ever had any negotiating function in relation to possible increases or anything of that kind?

PETER STEVENS: Not on that subject, no. We did, in the early days, make points in certain other aspects of the scheme. Particularly, one of the reasons why the MacFarlane Trust chose to get involved in the first place is that the indications from the original announcement and subsequent elaboration of that were that members of the -- registrants of the MacFarlane Trust would not be eligible because the government felt that they had already received sufficient, and we took the view that that gave us a little bit of leverage to ensure that our people, wearing my MacFarlane hat, as it was then, did participate as well.

JUDITH WILLETTS: Were those figures actually based on the Scottish model of payments. They simply fell in line with what Scotland had already decided, did they not?

PETER STEVENS: Yes.

JUDITH WILLETTS: Can I ask one or two more questions about that. How are people made aware of the fund -- of the availability?

PETER STEVENS: By the Department of Health and the devolved administrations using such resources as they have, which is probably not really very well.

JUDITH WILLETTS: So do they proactively write to the individuals who they would have, if you like, on their database, for want of a better expression?

PETER STEVENS: I think in some cases they probably have, but, as I said a few minutes ago, I suspect there are people without bleeding disorders in particular who are not aware that they are carrying the hep C virus.

LORD TURNBERG: Surely the Haemophilia Society make their members aware?

PETER STEVENS: The Haemophilia Society will make their members aware and the haemophilia centres will, I think, make sure that they follow up all of their patients.

LORD TURNBERG: Are all haemophiliacs members of the Haemophiliac Society?

PETER STEVENS: I very much doubt that. There is somebody else in the room who though know that is better than I do.

JUDITH WILLETTS: The payments are one time only payments?

PETER STEVENS: The payments of one time only, yes. We are not empowered to provide any support function. You know, we do not provide counselling or advice of any sort although we do occasionally point people -- if people ask us questions: what am I going to do with this money, we might suggest they take some independent financial advice or something but we are not empowered to perform any functions like that.

JUDITH WILLETTS: Are there any rules or restrictions surrounding those payments?

PETER STEVENS: About what people do with them?

JUDITH WILLETTS: Or whether they can at a later point make application or take legal advice or --

PETER STEVENS: I am not aware of any rules and restrictions along those lines. That was certain rules we have to follow in the case of payments to -- on behalf of somebody who has died but I think once the payments are in the recipient's hands, it is entirely up to them.

JUDITH WILLETTS: So there is no requirement for them to sign any form of waiver for example?

PETER STEVENS: No.

VIJAY MEHAN: Are they ring-fenced insofar that a payment does not affect their other means tested benefits once they receive a lump sum --

PETER STEVENS: Yes, they are.

VIJAY MEHAN: Can I ask one other point? Do you have a view regarding the eligibility and the retrospective application of the Skipton fund pre-July/August 2003 for bereaved widows? Do you have a view about why it is has not been applied retrospectively?

PETER STEVENS: I personally have a view but I think I am probably not at liberty to give my personal views.

THE CHAIRMAN: Can you just answer a factual question on that. Was it simply that when the scheme was announced it was not going to apply retrospectively?

PETER STEVENS: Yes.

THE CHAIRMAN: That was the reason?

PETER STEVENS: Yes.

THE CHAIRMAN: Could I ask one other thing arising out of all this? There is an appeal if you refuse an application.

PETER STEVENS: There can be an appeal.

THE CHAIRMAN: Can be. There is no appeal if you accept the application. No one from the department says "oh no, we are not going to pay this one."

PETER STEVENS: The department relies on us to make the decision or not and the department has never queried anything. I should say in respect of stage 2 payments, there is no such thing as a refusal. If we believe an application has come to too early and actually the physician or clinician does not provide any evidence of cirrhosis or cancer; what we will say to the applicant "I am sorry, you are not eligible yet but you are welcome to come back at any time." Although we would normally say probably not within a year.

THE CHAIRMAN: What lawyers call liberty to apply.

PETER STEVENS: Yes. Unfortunately once one has joined the club one will eventually probably at some stage become eligible at stage 2.

LORD TURNBERG: Can I ask about how you make a judgment: this one will go through, this one will not go through? What is the process? Who looks at the application? Is it purely based on the ticks in the boxes?

PETER STEVENS: All applications are reviewed by the administrator and by one of the directors. We are looking for the clinician to indicate that on the balance of probability the applicant was infected through NHS use of contaminated blood products. We do not necessarily want to see written evidence of that but we do want to know that the clinician has seen written evidence of that.

If the patient was identified, for example, by the lookback exercise done by the National Blood Service, then we know that that is automatically verified. If there are -- if the clinician can say that the hospital notes, notes in the GP's files, whatever, have indicated a blood transfusion was received, that is quite clear.

If there are no records at all of blood transfusion but the nature of the medical treatment that was received is such that it is highly likely that a blood transfusion would have been necessary, then we will say that (inaudible) balance of probability.

LORD TURNBERG: Can I interrupt you? If a haemophilia patient was diagnosed with haemophilia with a blood test showing there is hepatitis C in the blood that is an only --

PETER STEVENS: Yes, haemophilia patients get through very, very quickly. We do not even -- "even" is the wrong word. The stage of the form that asks about intravenous drug abuse for example does no have to be reached by a patient who has haemophilia. So if there might have been other contributing factors to the hepatitis C infection, for somebody with haemophilia, they are irrelevant. Somebody with haemophilia is deemed by the scheme to have been infected by NHS products.

LORD TURNBERG: So that hepatitis C in the blood and --

THE CHAIRMAN: Are you having difficulties hearing at the back?

VIJAY MEHAN: I think he can speak up.

LORD TURNBERG: A patient who has haemophilia, who was found to have a blood test showing they have hepatitis C is automatically included in the scheme irrespective of whether they have been a drug abuser, an alcohol drinker or other contributory causes. They are ignored because they have hepatitis C and they have haemophilia. Is that correct?

PETER STEVENS: That is correct.

LORD TURNBERG: Okay, fine.

THE CHAIRMAN: Anything else? This is not a public meeting. It is a hearing but we will make an exception. If there is a question you would like to ask --

UNKNOWN SPEAKER: What I would like to ask, the criteria for proving liver damage for a severe haemophiliac is actually a life threatening procedure in itself. To have a liver biopsy for a --

THE CHAIRMAN: In other words you say there cannot be a test for liver damage without a risk to the patient. Is that what you are saying.

UNKNOWN SPEAKER: Exactly.

PETER STEVENS: That is not the case. There are five or six sections of the stage 2 application form relating to the clinician's assessment of liver condition. Only one of those sections would require a biopsy and the haemophilia patients do not receive biopsies. There are many other ways of testing. Again it is judgmental by the clinician but providing the clinician does give an opinion, that signs of cirrhosis are detectable, whether these are chemical signs or signs of the field of the liver or whatever evidence he is using, provided he can say, yes, in my opinion cirrhosis is established, then that is sufficient and a biopsy is not required.

THE CHAIRMAN: I see, thank you. Right; anything, Mr Harvey would like to tell us?

MARTIN HARVEY: I am quite happy.

Just for a record, I am not a trustee of the MacFarlane Trust. I think it was said earlier "the directors of the MacFarlane Trust". I am a chief executive of the MacFarlane Trust.

THE CHAIRMAN: That is fairly normal in Trusts of this kind, is it not? Thank you very much.

We are now going on to the Eileen Trust. Is that right?

THE EILEEN TRUST

PETER STEVENS AND MARTIN HARVEY

THE CHAIRMAN: May we return to order, please? We now come to the Eileen Trust.

PETER STEVENS: Again, shall I make a few points?

THE CHAIRMAN: Would you, please.

PETER STEVENS: I know you have received the papers this time. I think you will find that in connection with the Eileen Trust I am no longer constrained by relationships with the Department of Health.

THE CHAIRMAN: I see, you can be indiscreet.

PETER STEVENS: The Eileen Trust was set up in 1993 on the model of the MacFarlane Trust after the result of campaigning from various sources, particularly Gary

Kelly who I think gave evidence at the last --

THE CHAIRMAN: I am afraid -- I can understand that people are having difficulties in hearing at that end but there are also having difficulties hearing at this end unless we can maintain an element of silence.

PETER STEVENS: The Eileen Trust is very much smaller than the MacFarlane Trust. We have had fewer than a hundred people registered so far with it and probably about half of those registrations were made posthumously. The Eileen Trust provides support to people who were infected with HIV through National Health Service treatment, who do not have bleeding disorders. So these are people who received --

THE CHAIRMAN: Oh, I see.

PETER STEVENS: -- a blood transfusion in the course of a routine operation or maybe something that was not so routine.

THE CHAIRMAN: So the MacFarlane Trust deals with people who are haemophiliacs. The Eileen Trust deals with people who have the same misfortune but were not haemophiliacs.

PETER STEVENS: Yes. Some of the people rather like a mild haemophilia will have had one course of medical intervention that required a blood transfusion. Some have more complicated, underlying medical conditions that might have required a number of infecting treatments.

There is a very wide range of medical conditions that has been involved. We are currently looking after 27 registrants, which is as many as we ever have looked after at any one time. The needs of the registrants are increasing as they live longer. Their health deteriorates, their ability to look after themselves deteriorates, relationships with the other people come under strain, marriages break up, many of them are living in acute financial distress. So their needs are increasing.

Unlike the MacFarlane Trust, we are getting new registrants, we have had seven new registrants in the last five years. Now, this is not people who have been infected in the last five years; the window of infection was about the same as that for the MacFarlane Trust; 1973 to 1986. But because these people do not have bleeding disorders, might have had an one-off medical treatment that was resolved, and then they went back to their life, nobody followed them up, nobody had any reason to follow them up and say "oh, by the way, we pump some contaminated blood into you". So we have people who are coming to us and have been HIV positive for over 20 years and have received no medical attention for that condition in that period until quite recently, when suddenly constant ill-health may have become a problem and suddenly people realise what the problem was. I cannot believe that the latest registrant, who arrived a few months ago, is the last. There are others out there; who have HIV and are in the community, maybe married, a source of further infection. I think it is a very serious problem. There may not be many of them but it is very serious.

THE CHAIRMAN: Are you suggesting that the government might take a proactive line on this and try and make it more widely known?

PETER STEVENS: We have suggested that the Department of Health is might be a good idea from time to time. A few years ago they put a notice in the Chief Medical Officer's bulletin, that is a weekly or monthly publication that goes to all medical practitioners and hospitals. It is a 20 to 30-page document and a couple of paragraphs on page 16 may not be the most appropriate method of drawing attention to a serious problem. I am not aware that anything like that has happened again.

We are all aware that the cost of living is rising. That is not recognised in the funding that is provided to the Eileen Trust. The Eileen Trust was set up with a fund of half a million pounds in 1993 and, because there were not many people drawing on it, and as a result of investment activities, that half a million lasted pretty well until about 2001, when it was followed by a further £500,000. Because there are more people now drawing on it, and because the trustees are faced with higher requirements from people, that half a million pounds did not last so long. The department has now switched to annual funding at a rate at the moment of £177,000 a year to include operating costs.

We have had indications from the Department of Health that that level, which they gave us last year and this year, will be the same for next year as well.

JUDITH WILLETTS: This is without the section 64 administration money.

PETER STEVENS: Section 64 administration money is being withdrawn at the end of the current agreement, which is this year and after that we have to find our own operating funds out of the £178,000.

THE CHAIRMAN: Were you given any reason for that? A reason you can tell us.

PETER STEVENS: I have a letter from the department saying:

"You may be aware that the department is facing another difficult year ahead."

My heart bled. Our registrants have no capital resources on which to fall back. People who registered with the Eileen Trust do receive the same capital payment as was received by the MacFarlane Trust people through the special payments operations in 1990 and 1991. However, those capital payments were assessed or were judged in 1991, it seems rather strange that the same sums of money are still being given in 2006 and 2007.

We were recently told by the department that the first port of call for financial support for registrants of the Eileen Trust should be the benefits system and the Eileen Trust should only be providing top-up facilities. This is the first time I have ever heard this statement made by the department in respect of either trust. It is totally new philosophy, if you like. The benefit system is not in my opinion well suited to provide for people with multiple medical conditions, who are permanently unable to work because of those medical conditions. Increasingly the benefits system is being designed to encourage people to go and do some work.

That may be quite understandable from the government's point of view but it does not apply fairly in my view to the registrants of the Eileen Trust. Local authorities are cutting back to the support they give. It is becoming much harder for people to obtain services and support from them. The

National Health Service is cutting back to the services it provides. Dentistry is fairly obvious case and for people who are HIV positive dental health is very important to avoid a further source of infection.

So the Eileen Trust is being required to give more support to more people on several fronts with declining funding at least in real terms, if not in actual terms, from the Department of Health.

There is an additional issue, as regards the Eileen Trust, which makes it unique, I think, or makes it different from the MacFarlane Trust.

Registrants to the Eileen Trust were infected through blood transfusions. I am not a medical Hirst original but I believe blood transfusions have been going on for centuries and the treatments that these people were receiving were not being provided by hematology. They were being provided by orthopaedic surgeons by heart specialists whatever, a range of clinicians who would reasonably expect, if their patient required a blood transfusion that the blood transfusion would not be a source of infection, they could not be expected to know that they were actually putting a life-threatening treatment into their patients.

To my mind this makes the Department of Health even more responsible for the condition of the Eileen Trust registrants. I am not talking liability, which can be discharged. I am not talking blame, which can be excused. I am not talking accountability, which can be referred upstairs. I am talking responsibility, which is permanent. I think the Department of Health are turning away from their responsibility. They are denying responsibility for the Eileen Trust registrants by cutting back the funding and by refusing to give adequate funding to the individuals as well as to the trust. It is a total abdication of responsibility.

As far as what might be done in the future, there seems to me to be three possible stages, or three possible grades of solution. The easy one is simply to give the Eileen Trust more funds so we can do our job better. A better solution would be to combine that with renewed capital payments to the registrants, to give them a measure of ability to look after some of the needs that we cannot provide for.

The best solution -- remember, we are only dealing with just over two dozen people at the moment, although there may be some more coming along -- will be a substantial capital payment to the registrants, of the sort that has been indicated in a similar case and was settled out of court a couple of years ago, to give the registrants independence and the ability to make their own decisions and the ability to provide for the security of their dependents.

THE CHAIRMAN: In other words, a capital sum which will provide an income.

PETER STEVENS: Yes, and basic security. The trust could possibly be kept going on limited funding. They aim to be able to deal with crises, which do occur from time to time and maybe to provide more general, non-financial support services. But the present situation is insupportable.

That is all I have to say.

THE CHAIRMAN: Thank you very much. You have made it very plain.

LORD TURNBERG: Just to clarify, this group of patients are really quite different from the haemophilia patients, in that they were not subject to the use of factor concentrates from America, from abroad. These were UK blood transfusions from UK patients that these patients received -- is that correct? -- and that is why the numbers are so very much smaller, considering the vast numbers of blood transfusions that were given.

PETER STEVENS: Whether the blood came from UK sources or was imported, I do not know, but the blood transfusions were administered by the National Health Service.

LORD TURNBERG: It is very difficult to import blood very far.

PETER STEVENS: Some could have been frozen.

LORD TURNBERG: Okay. If I get you correctly, the government's arguments are that there is a benefit system available and this is a sort of modest supplement --

PETER STEVENS: That seems to be the argument that is now being put forward.

LORD TURNBERG: And the arguments that you would like to see accepted are there should be more money in the system for this small but severely affected group of patients?

PETER STEVENS: Yes. As I said, the Department of Health was responsible for their condition. I believe through us the Department of Health should maintain that responsibility --

THE CHAIRMAN: Responsible morally, not legally? Or are you asserting that there is a legal responsibility? Or leaving that one open.

PETER STEVENS: I will leave that one open. I think probably -- how to define that is your side of the table rather than mine.

THE CHAIRMAN: Indeed, but you were saying there is a moral responsibility?

PETER STEVENS: Certainly there is a moral responsibility.

LORD TURNBERG: Thinking about how much this would involve, when you talked about a large capital sum which would then provide an income, presumably you can calculate that out from the age range of the group of patients and the numbers involved. Do you have a figure?

PETER STEVENS: No, I do not. The case that was referred to in the report put out by the MacFarlane Trust, which contained an appendix about the Eileen Trust -- there was a case -- who settled on
three quarters of a million pounds for infection with a similar virus through the National Health Service. If one was to take that as a figure -- as a benchmark, but to adjust for the case that some of our registrants are very old -- one is very young, is eight -- yes, one could come up with an aggregate figure and it may well be something less than 27 times three quarters of a million pounds.

But supposing we are going to be talking £25 million in total, I do not believe that the Department of Health would have much difficulty in finding it. As I have said to them, the civil servant who looks after us at the moment, he will be retiring in a few months' time on an index-linked final salary pension fund that is not financed --

LORD TURNBERG: (inaudible) in the other trusts.

PETER STEVENS: In an embarrassing position, which I would be delighted to see them in.

THE CHAIRMAN: You might encounter the thin end of the wedge argument, I suppose.

PETER STEVENS: I would love to be the thin end of the wedge. Now that I no longer have any official concerns for the MacFarlane Trust, I would love the Eileen Trust to be the thin end of the wedge. Hitherto in this inquiry you have been hearing evidence from two relatively large groups of articulate people, those with haemophilia and HIV -- mostly hep C as well -- and those without haemophilia and hepatitis C. The Eileen Trust is a little group in the middle, a tiny, tiny, group, but their needs are just as important, just as urgent, as any of the others.

JUDITH WILLETTS: Surely, were capital payments to be made, people should not be discriminated against based on age because surely there are also dependants and --

PETER STEVENS: Certainly the needs of some would be -- there would be a degree of difference in need and one would have to think about that.

JUDITH WILLETTS: Have any of the registrants explored the benefits route, to see what may or may not be available for --

PETER STEVENS: Most of them have to.

JUDITH WILLETTS: They are already doing that?

PETER STEVENS: Yes, most of them have to.

JUDITH WILLETTS: So the department saying that is simply stating something that people would naturally have had to do. I understand the point you are making about it.

PETER STEVENS: The important thing is that three years ago the department would not have said that. They would have thought of the benefits system as being supplementary to us. They have now reversed it. I would like to say that this statement was made to the official to clarify something that the minister said to us along the same lines. This is not just official thinking, this is government thinking.

JUDITH WILLETTS: You have also suggested that there is quite a lack of understanding at quite a senior level because of expressions used such as "the remaining registrants". There seems to be a lack of understanding that this is a group that could become larger.

PETER STEVENS: There appears to be a lack of realisation that this is a group that could be and probably will be larger.

THE CHAIRMAN: You mentioned a few moments ago someone who had taken legal proceedings and you told us about the settlement. Is there a likelihood of further legal proceedings (inaudible) number of people or --

PETER STEVENS: I think this is highly unlikely. This was a particular case of somebody who was infected with HTLB3, I believe. I do not know -- it never reached court; it was settled out of court. So all one knows is it happened and they settled three quarters of a million pounds and it was about two or three years ago, the settlement.

JUDITH WILLETTS: Who settled? Where did the payment come from?

THE CHAIRMAN: The department, presumably.

PETER STEVENS: I believe so.

THE CHAIRMAN: Yes.

Could I just ask one other thing? Are payments in any way dependent upon the approximate date of the infection? If it were after a certain date or ...

PETER STEVENS: Payments from the trust?

THE CHAIRMAN: Yes.

PETER STEVENS: No, as I said, the period of infection was quite -- the window was quite short, from 1983 to 1986 roughly, that period. That is when all of our people were infected, the same as the registrant to the MacFarlane Trust.

THE CHAIRMAN: That just happens to be a fact; it is not a requirement.

PETER STEVENS: No, because after that time the blood and blood products were treated to eliminate the virus.

THE CHAIRMAN: Yes.

PETER STEVENS: I think it is worth commenting, obviously without knowing the names, that one of our recent registrants, a lady who carried the virus undetected for 20 years or so -- the particular effects of the virus on her were mental; they got into her brain. It has cost her husband -- it has cost her family, but her husband -- about £200,000 to look after her. The family's savings have gone. A daughter who was going to university could not go to university. A man who was independent, self-employed, is now drawing benefits.

THE CHAIRMAN: We have some evidence of some of these things.

PETER STEVENS: It is quite disgraceful.

THE CHAIRMAN: Thank you very much.

JUDITH WILLETTS: Thank you.

THE CHAIRMAN: Now we come to the MacFarlane Trust.

MACFARLANE TRUST

MARTIN HARVEY AND CHRISTOPHER FITZGERALD

THE CHAIRMAN: May we proceed? Are you going to base your presentation on the statement which we have?

CHRISTOPHER FITZGERALD: Yes. I am not going to speak at length. If I may, I will say a few introductory --

THE CHAIRMAN: Please feel free.

CHRISTOPHER FITZGERALD: Unlike the two previous presentations, I will expect that a number of the questions, if not most of them, will be answered by Martin Harvey. The reason for that is, as you may be aware from the paper, I have only very recently taken the chair at the MacFarlane Trust. Obviously, I am well into my seat now but I am not as fully briefed on the detail, certainly on the detail of the history, as Martin is, and indeed Peter was.

What I would like to do, if I may, is, without going through the paper itself, just develop the theme of the commitment of the government and to contrast that with the delivery of the funding which I would say has been committed.

If I may, I go back to 1989, when the commitment was expressed by the then government in the following terms:

"The government shares the universal sense of ...(Reading)... of the unique position of haemophiliacs who have been infected with the Aids virus."

1990:

"The government has always recognised the very special and tragic circumstances of haemophiliacs infected by HIV and their families."

Then, moving on to 1999, by then obviously a new government:

"We will, of course, continue the commitment to provide the finances which you need for the trust fund."

Then 2006, the Secretary of State:

"The government takes the issues of haemophilia and blood products very seriously and has great sympathy for anyone who has suffered harm as a result of NHS treatment. Ministers do understand the hardship and great distress that people ...(Reading)... from HIV and then from hepatitis C and deeply regret that so many people were infected by blood products."

You can contrast that with the delivery. The reality is that there has been no effective increase in the funds available to the MacFarlane Trust since 2003, and we are told, as you have heard in the context of the Eileen Trust as well -- we are told not to expect any increase in 2008/2009 either.

Over that period the number of infected -- the registrants, the victims -- has barely reduced. It has reduced, there have been some few difficulties, but the rate of reduction is now happily very slow. But the number of other beneficiaries, "infected intimates" and also widows and children, has substantially increased.

Against that background too of an effective increase, we have to keep in mind a point that Mr Stevens made to you a moment ago, that the cost of living that our beneficiaries are subject to is much greater because of their special -- unique needs than it is for others, and indeed rises more rapidly.

Against that, we received a final letter from the Department of Health, from the official in charge of us at the moment in November 2006. What she said was:

"I explained the financial difficulties facing the department, and I am being asked to reduce all budgets. Nevertheless ... "

And this was the sop to us:

" ... I am aiming to secure the same level of funding for 2007/2008 as 2006/2007."

Which was at least some advance on the previous threats of actual reduction.

Our response to this was that the unique circumstances of the beneficiaries of the trust, which, as we have said, was recognised by many ministerial statements over the years, justifies the considerable increase -- and this was a considerable increase, which we set out in the case -- in funding long-term survival, which is referred to in the paper.

THE CHAIRMAN: Incidentally, I certainly have not, and

I imagine we have not, seen a copy of that.

CHRISTOPHER FITZGERALD: You have not seen the whole paper, you have the executive summary. We can give you the whole paper.

THE CHAIRMAN: Personally, I would be grateful to see the whole paper.

CHRISTOPHER FITZGERALD: We have them here. We did not know how much you wanted to read before today. We said that, while the establishment of the trust recognised the uniqueness of the situation, at the same time it carried the risk for the trustees that it might be perceived to have moved the plight of the beneficiaries from being a political issue to an administrative problem and we said it would be most unfair, not only to the trustees but, more importantly, for the beneficiaries, but also for the administrators. In order for the trustees to achieve the objective in the trust, which must have been a political intention, a renewal of political commitment to those objectives is required.

It is wrong for our beneficiaries, we said, whose lives are continuing, and will continue, to be blighted by errors within the NHS, that they should be further disadvantaged by financial stringency within the NHS. That is what we said to them.

I would simply wish to reiterate that it is simply unacceptable on any basis, whether you call it moral legal or whatever -- it is simply unacceptable that the funding the consequences of the greatest catastrophe in the history of the NHS should be constrained by the current financial difficulties or incompetencies in the NHS.

I concluded in our paper -- and I will repeat -- that what is needed is a renewal of the political commitment. No amount of arguing the toss -- dare I call it that -- with notions about what the cost of living is and what the differences in the cost of living are is going to make any difference. This is a political matter.

When the trust was set up, and repeatedly since then, ministers have accepted the obligation. Whether you call it a legal one or a moral one or you simply call it responsibility, they have accepted responsibility.

We, the MacFarlane Trust, are a charitable trust. The trustees are individuals, volunteers, who want to do what they can to help people in these tragic circumstances. We are charged with a duty under our trust deed to relieve the needs of our beneficiaries. We cannot perform that duty unless adequate financing is provided, and to do that the government has got -- the politicians have got to recognise the fundamental change that has taken place in the needs of our beneficiaries, resulting from the fact that they are now expected to survive for a full lifespan, God willing, whereas, when the commitments were originally given, they were all expected to be dead within four to five years. And there are realities here, new realities, that are going to continue and must be recognised.

That is all I would like to say at the moment but please ask all the questions you would like and Martin will endeavour to answer most of them.

MARTIN HARVEY: I have nothing to add to that, Mr Chairman.

THE CHAIRMAN: I see that the trustees are appointed basically from three constituents. Perhaps I should not ask this question, but is there any difference in the views of the trustees depending on which constituents they come from, above the --

MARTIN HARVEY: No.

CHRISTOPHER FITZGERALD: I have been a trustee for long enough to have heard them all speak on this subject and I am sure that many of them would speak in even more colourful terms than I have done. There is absolutely no doubt -- the 10 trustees are mainly those who were responsible, jointly responsible, for the case that was submitted in 2005, and the new members of the board are fully supportive of that.

THE CHAIRMAN: Thank you.

MARTIN HARVEY: Sorry, if I may add, I am also very pleased to be able to say that they all take their individual responsibilities as trustees very seriously, in that they do not represent anybody. The trustees are all trustees and their only objects are to support our beneficiaries. They are not answerable to the department.

THE CHAIRMAN: Appointed by the department but not spokesmen for them?

MARTIN HARVEY: They are not even answerable. Once they have been appointed, the door closes and it does not matter who they are. The same applies --

THE CHAIRMAN: It certainly would be seem odd if the department could decide to remove a trustee.

JUDITH WILLETTS: But they do nominate trustees.

MARTIN HARVEY: Yes, they do.

THE CHAIRMAN: Personally, I would like to hear a little more about how payments are calculated. Could you tell us about payments to the registrants?

MARTIN HARVEY: As the submission made clear, some years ago the trustees took the view that the majority of payments to the registrants were made by monthly payments. At the moment there are two classes of monthly payment:

what we call a standard rate and a higher rate. The higher rate comes into play depending upon the registrants' entitlement to benefits.

Very briefly, if you receive income support and the yearly premiums that are attached to that, you will get the higher rate from the MacFarlane Trust of £300 to £500 per month. That is the basic higher rate. If you are on the standard rate -- and that means that you are not in receipt of income support -- that might be because your wife or your partner has a job -- then we would pay the -- the trust would pay the standard rate of pay, which currently is £255 per calendar month.

Some 70 per cent or thereabouts of the funding allocation is taken up by regular payments, and on top of that we have two annual payments. The rest is disbursed by way of single grants for a variety of different purposes.

THE CHAIRMAN: That is if you require -- if you reached the stage where you --

PETER STEVENS: It could be whatever it might be, but we publish -- as you are probably aware, we publish office guidelines which you can apply, and indeed you are at liberty to apply, for almost anything, if it is related to what the trust does.

THE CHAIRMAN: Again I think it might help us if we could have a copy of the guidelines.

LORD TURNBERG: Can I ask about numbers of patients and people who are on your books? What sort of numbers are we talking about?

MARTIN HARVEY: The registrants -- we are about 370 from the original core number of 1,246. We have some 42 infected intimates.

LORD TURNBERG: What was the number you had to start with?

MARTIN HARVEY: 1,246.

LORD TURNBERG: So there are 370 still alive?

MARTIN HARVEY: Still alive. We have 41 infected intimates and we currently are in touch with, or support some, 200 non-infected winners, with or without dependants.

LORD TURNBERG: How many of the patients do you know have hepatitis C as well?

MARTIN HARVEY: All the registrants are deemed to have had hep C or are currently infected.

LORD TURNBERG: As well as HIV?

MARTIN HARVEY: Yes.

LORD TURNBERG: So they would come under the Skipton Fund as well?

MARTIN HARVEY: Indeed. As you probably recall from Mr Stevens' earlier evidence, when the MacFarlane Trust was invited to advise and guide the department (inaudible) disbursement programme, part of the arrangement was that MacFarlane Trust registrants were deemed to qualify as a matter of course, which would be the case. And so you are correct, sir, that the fact that trust registrants do have a (inaudible) as well and have gained -- received ex gratia payments through the fund.

LORD TURNBERG: Okay.

VIJAY MEHAN: Could you tell us a little bit about the matrix of payments? For example when they were made in 1991 to, say, a child or a married adult, and how much money was paid.

MARTIN HARVEY: I think you are referring, sir, to the MSPT and MSPT2 payments, rather than the year by year support that the MacFarlane Trust itself gives. Am I correct in that?

VIJAY MEHAN: Yes.

MARTIN HARVEY: The MSPT payment was a one-off payment of £20,000, an ex gratia payment that was made at that time. The MSPT2 payments were made in 1990 and 1991 and were the payments subject to a waiver, and I have a copy of the MSPT2 waiver here if you would like it. (Handed)

The MSPT2 payment, in terms of values, was determined by the department. The MacFarlane Trust was the vehicle for delivery, as far as I am aware -- and you will appreciate it was quite before my time -- the

MacFarlane Trust (inaudible) had no negotiated powers to establish values. It was a settled sum and the payments were according to your matrimonial status, whether you had dependants, your age --

THE CHAIRMAN: So there was a sliding scale of payments?

MARTIN HARVEY: Yes, there was.

LORD TURNBERG: Can I just go back on this because I am not sure that -- a patient with haemophilia who has HIV and has hepatitis C is on your books and on the Skipton Fund's and now is able to get a payment from your fund, and the capital sum, 20,000 or whatever it is, from the Skipton Fund. Is that absolutely correct?

MARTIN HARVEY: Indeed, but the MacFarlane Trust registrants have received the first payment from the Skipton Fund, the DDS -- those that have applied, of course.

LORD TURNBERG: Those that have applied.

THE CHAIRMAN: You said those rules applied. Do you think there may be a number of people who might be eligible but --

MARTIN HARVEY: To the best of my knowledge, chairman, the vast majority of MacFarlane Trust registrants have applied. Being the chief executive of the MacFarlane Trust and indeed the director of the Skipton Fund, I do keep a gap between those two functions, and my function with the Skipton Fund is perhaps more of an administrative nature, rather than, as Mr Stevens referred to, of assessing forms and looking at individual applications.

From a MacFarlane Trust point of view, I can find myself in a position of perhaps assisting a registrant of the MacFarlane Trust in terms of his relationship with the Skipton Fund, so I therefore try and perhaps keep a gap of some -- to ensure that clarity remains, if I can put it like that.

THE CHAIRMAN: But you are dependent to some extent -- totally, presumably -- on the advice to make an application which people are given by the consultant or --

MARTIN HARVEY: I think we are going back into the Skipton Fund.

THE CHAIRMAN: This is what was said about the Skipton Fund.

PETER STEVENS: Just as a point of fact, the Skipton Fund -- first stage payments to 359 MacFarlane Trust registrants. It is possible that a few have not got hepatitis C.

THE CHAIRMAN: What I was wondering at this stage, though, was simply whether there were people that were told that they could apply to the MacFarlane Fund. Is that a possibility?

MARTIN HARVEY: In terms of MacFarlane Trust special payments trust or the MacFarlane Trust per se?

THE CHAIRMAN: The MacFarlane Trust, I was thinking of, per se at this stage.

MARTIN HARVEY: Indeed. If one looks at the time when the trust came into being in 1988, the numbers registering with the trust, I think -- as I recall, the maximum number we had, as it were, on the books was something in the order of 900 to 1,000. But, of course, many have passed away in between that time and there would have been an ongoing registration and, I suppose, a deregistration.

I am not sure of the publicity of the MacFarlane Trust, as and when it was set up. I am not aware. I am aware that I would be surprised if we missed, as it were, any registrations from those that were able to register with the MacFarlane Trust. I do not know what the publicity given to the MacFarlane Trust was at the time.

THE CHAIRMAN: No, I see, thank you.

MARTIN HARVEY: But I think, given the very public way in which this was disclosed -- discussed -- back in 1990 and particularly the lobbying efforts from the Haemophilia Society, that it is very, very surprising if any of their -- certainly any of their members failed to register with the MacFarlane Trust. There may be other haemophiliacs who -- (Overtalking).

UNKNOWN SPEAKER: Could I just add, there are a number of people who I believe have not been paid for reasons of stigma, reasons of keeping it within the family, and I certainly know of one person who was only paid two or three years ago because she is a widow and she never, ever knew that her husband was HIV positive.

THE CHAIRMAN: Yes, thank you for that.

LORD TURNBERG: Are you having many new registrants?

CHRISTOPHER FITZGERALD: No. There have not many since 1990/1991.

MARTIN HARVEY: We have had in my time imposed three infected intimates. But the number of people supported by the trust -- this goes back to a point that I was making in my introduction -- the high water mark -- if I can recall, that was 970 by the time the trust actually got going because the 1,270 that has been referred to or something were already dead by the time the trust was established. But we now support 700 in total. It has not actually changed that dramatically, although so many of the victims have already died.

LORD TURNBERG: Can I ask what the main causes for concern are? Is it primarily with the size of the grants given to these patients or relatives or is it that some who deserve compensation in some form or another are not getting it, or is it both?

MARTIN HARVEY: We, of course, have to be very careful talking about compensation. I know the victims -- those who have been harmed, wish to look -- and you can understand very well why they would wish to look at the payments they receive as compensation. We are charged with relieving need --

THE CHAIRMAN: We are do this neutrally -- (Overtalking).

MARTIN HARVEY: Being charitable trustees, we have to relieve financial need and we have to establish need in the first place -- financial need, that is -- and that is what we have to relieve. So that indeed is our concern, that there are needs that our very special community of beneficiaries have which are not being properly provided for. These are people who -- Mr Stevens referred, in the context of the Eileen Trust, to similar conditions. These are people who believe they would have had -- there is absolutely no reason to doubt that belief -- they would have had what we all consider, sitting round this table, to be normal lives. The ability to have a normal life has been taken away, not through any fault of theirs. but clearly through the fault, whether or not it amounts to legal liability or not -- through the fault of a National Health Service.

So you can see where the victims would be coming from in their expectation, but there are needs -- to live a life at the level of income support is not what these people would have expected to be able to do.

Many of them would have had top, high-flying jobs. Many of them would have had very good jobs but they are unable to live that life and unable to provide for themselves, and their families and for their dependants when they are dead, in a way which other people would expect to be able to today.

LORD TURNBERG: Leaving aside the fault and compensation business, the argument is primarily, if I understand it, that the size of the grants are too small, rather than that there is a group of people out there who do not have access.

MARTIN HARVEY: We have no reason to believe that there is a group of people out there that we are not providing for.

THE CHAIRMAN: There are payments which you would have made, and properly made, but you were constrained because you yourself are not properly funded?

PETER STEVENS: Yes, which is the case made, for better or worse, in funding survival.

LORD TURNBERG: There is not a question around whether widows or dependants are not getting what they should get? Is that an area that is a problem?

MARTIN HARVEY: Yes, very much so. It is in the same vein that we feel that they should --

LORD TURNBERG: They have access but not to enough?

MARTIN HARVEY: Yes.

VIJAY MEHAN: Could I ask you a little bit about -- you say in your paper that the funding of long-term survival, I think, asks for a figure of 7.5 million per annum and I think the Department of Health responds in their document, "The Full Life, Not Just Existence". Did they just reject that out of hand and what did they -- how did they respond and how was your response to their response?

MARTIN HARVEY: "Full Life, Not Just Existence," was in fact the long-term review document, and the business case for funding long-term survival was born out of the long-term review, as it were. So the two are two separate documents.

THE CHAIRMAN: I follow that. We have not -- at least I have not seen either -- do you have copies of the Department's document? We can get it from the department, if necessary.

MARTIN HARVEY: No, they are both our documents. They paid for the first. In other words --

THE CHAIRMAN: I follow that. They funded the first.

MARTIN HARVEY: But both documents were produced by the trust -- by the MacFarlane Trust.

THE CHAIRMAN: So you can let us have both documents?

MARTIN HARVEY: If you would like to have them, absolutely. But the response is attached at annex B. Annex A was the executive summary of the funding long-term survival, and the Department did not address the paper in any detail at all, just that we are satisfied that if we -- rather than give you what you want, which was effectively an increase of close to 100 per cent, something of which they identify as 10 to 11 per cent, was enough.

THE CHAIRMAN: Which, presumably, as I understand it, was enough to continue at the present level allowing, I suppose, for more registrants.

MARTIN HARVEY: Within the policy framework adopted by the trust, yes. But that 11 per cent calculation, how it was arrived at, we were -- unclear in that sense and it seemed to embrace a number of constituent factors which would not necessarily reflect a 11 per cent increase if it was taken at its -- what you would believe it to be. There were some conflicting assessments in terms of how they arrived at an 11 per cent increase, which we managed to demonstrate to the department in that sense.

MARTIN HARVEY: That was the nature of the response; that this is not 11 per cent, it is a very great deal less and actually amounts to barely anything at all. Going further, the response continues, I see it very much as part of my function, probably the most important function, that I have to keep pressing, find other ways of making this case, they are simply not going to address the case that has been made. We will just have to find another way of presenting it and just keep going because --

THE CHAIRMAN: In essence, the discussion has not really moved forward from the point where that letter was sent.

MARTIN HARVEY: No, the response we get now is not that we do not agree with your case. They simply park that to one side. They say we cannot afford it because the Department of Health does not have enough money.

LORD TURNBERG: You are seeking, roughly, a doubling of your current --

MARTIN HARVEY: Yes.

LORD TURNBERG: Certain other difficulties in the way the trust is addressed by the department have occurred recently. By way of illustration, we are now funded quarterly in advance where, initially, for this current financial year, the department was seeking to fund us quarterly in arrears. That caused me, as the chief executive some distress where, hitherto, we have received the global allocation for funding in one, as it were, block sum; not this year, not the previous year, before that, where we were able to prudently manage that sum to ensure that we gained income which could be transferred to the fund for this purpose, we could not effectively increase the fund for disbursement. That now is denied us, in that sense, where we are funding quarterly in advance. You can imagine the ability to attract interest income has largely gone.

It is matters such as that which, as well as the no real increase in funding at all, it is the continuing chipping away, as it were, of our ability to try and meet what we are seeking to do.

THE CHAIRMAN: In the old days the government would have called it an interest account, your interest account has gone. So you have to incur the debts and --

A. Yes, it is a balancing act. But of course, the department would say they want a reasonable expenditure profile to take place. Of course, administering a trust such as the MacFarlane Trust does not have a reasonable disbursement profile to try and match a reasonable expenditure profile from the department. Needs from beneficiaries come in and the job of the trust is to meet those within the policy framework and to juggle the funding requirements of the department in terms of what we do as a trust, can prove onerous.

JUDITH WILLETTS: Sorry, the letter from the minister, the MacFarlane Trust and Eileen Trusts have been, to put it slightly crudely, lumped together.

A. Which was news to us at the time because of course they are two separate chartable bodies and and it would seem to me that there was a wish to try and put them together, when of course we cannot and that was made clear to the department in that sense. But of course the letter, of course, in terms of popular funding as well and that would be totally inappropriate.

JUDITH WILLETTS: Is this the first time that it was stated that those figures include the provision for the admin course? Is that the first --

MARTIN HARVEY: Yes, the MacFarlane Trust had an section 64 grant as well. And probably for quite good reasons. The sum of the section 64 grant to fund the MacFarlane Trust was visibly higher and I think the department sought to make sure section 64 went elsewhere and we were taken out of that, which I have no quarrel with, in that sense. But that is the case now, yes. We have to, as it were, run a separate budget for administration costs within the global allocation for funding.

THE CHAIRMAN: So they have run together. In their minds at least, the core funding with the --

MARTIN HARVEY: Yes, we get a grant and that is the grant but we try and meet the guidelines to keep our administration -- do meet the guidelines to keep our administration costs well below 10 per cent of the global funding allocation.

JUDITH WILLETTS: So that is effectively a reduction?

MARTIN HARVEY: Yes.

THE CHAIRMAN: Thank you very much.

UNKNOWN SPEAKER: There is a lady here who desperately would like to make a point.

UNKNOWN SPEAKER: It is a funding issue. My late brother was a haemophiliac who got a one-off payment but because he was 17 when he got his payment -- he was not married, but because of his HIV status he was never going to marry and never have children, so he was discriminated against in terms of, there was funding but it was my elderly mother and my elderly father and his immediate family who had to look after him which, of course, we do not mind at all but he actually had his ability to have care from a family unit taken away.

THE CHAIRMAN: We have had that point made quite forcefully to us.

UNKNOWN SPEAKER: That is fine, sorry. That is okay.

THE CHAIRMAN: Thank you very much.

SCOTTISH HAEMOPHILIA FORUM

PHILIP DOLAN

PHILIP DOLAN: Unlike the previous submissions that you have had, we do not have money. We are an organisation that is funded purely from what our members take out of their own pocket, so hence, we do not have the big machinery behind us although we do get the support from the Haemophilia Society.

VIJAY MEHAN: Would you just say where you are from.

PHILIP DOLAN: I am Philip Dolan, I am the chairman of the Scottish Haemophilia Forum. I am also a trustee of the Haemophilia Society and a trustee of the MacFarlane Trust.

THE CHAIRMAN: Just to clarify, is the Forum a charity?

PHILIP DOLAN: It is part of the Haemophilia Society. We set it up as a group of individuals.

THE CHAIRMAN: So it is a group within the society?

PHILIP DOLAN: Yes. We, in fact, got the imprimatur of the Haemophilia Society some years ago. But operate within the issues of the Scottish Parliament and looking at campaigning in Scotland. I do not propose to read all of what I have put in there but I would like to clarify; the bits with my submission, which takes 11-pages, the first part of 11 pages, others have appendices related to what I am saying. If it is necessary, I will read it all out. If not, I can paraphrase. So long as the details of my submission is included in the final draft of any papers.

THE CHAIRMAN: We will certainly read what you have submitted and take account of it.

PHILIP DOLAN: I will speak to most of it. As I said at the beginning, the Forum is part of the Haemophilia Society but working within Scotland. Like many of us, we campaigned from way before 1999 to Westminster and Scottish MPs did, in fact, carry out and get adjournment debates in the Westminster Parliament in the mid to late 1990s, before the Scottish Parliament came into being.

As a result of the Scottish Parliament going into being, we campaigned there but obviously, we have had a different approach to the Parliament. The Parliament has taken a different approach altogether with haemophilia. But, perhaps if I go to August 1999, as a result of a meeting with the health correspondent of the BBC, the story was of interest to the BBC Scotland, who ran it on 6th August, right throughout the day from 6 o'clock in the morning, both radio and television. At nine o'clock, I think, I had the television companies from all over the UK and people trying to get me to speak. So we had media cover for several days thereafter. This resulted in the Health Minister interrupting her holiday and assuring us she would meet us to discuss the problem. On 14th September of 1999, she met with myself and the chief executive at that time, Karen Patheheim(?) of the Haemophilia Society and Chris Hodgson also was present, as was one fellow colleague, [redacted], [redacted], like a number of others, is now dead. The minister subsequently agreed that she would set up an enquiry, an investigation, and this investigation took about a year for them to respond. At the end of this, the Health Committee and any other person in Parliament recognised it had been a whitewash because the people who carried out the interview was a senior adviser at the Health Department in Scotland and a civil servant, who interviewed the Blood Transfusion Service but not the patients with haemophilia, not the haemophilia organisations and they maybe had a cursory contact with some haemophilia doctors.

During this period of time there was a motion placed before Parliament and 80 MSPs from all parties signed that MSP. As far as we are aware, this is a petition that has had the highest number of signatures from members of the Scottish Parliament. 80 means out of 129 MSPs -- take away ministers, deputy ministers, conveners -- you virtually have most MSPs supported that at that time.

During the evidence the health -- after the ministers' investigation was deemed to be a whitewash, the Health Committee of Parliament decided that they would have their own investigation and they then carried out -- but they had limited sources of doing things but they, in fact, did have -- hear evidence from myself and colleagues. They heard evidence from the Blood Transfusion Service. But what was missing was a lot of facts -- they did not, for instance -- the Blood Transfusion did not admit or acknowledge that in Scotland during the 1960s, 1970s and 1980s, they were getting blood donations from Scottish prisoners, which, as most of you will know, is a fairly high risk group of people to take blood from and I can assure you, because I was the chairman of the Parole Committee for two of the large prisons, I am conscious of the status of prisoners.

They did not give any information about the fact that the blood protein centre in Scotland had had difficulties with the fact that the -- in the 1970s lost their licence but carried on producing on the basis that they had crown immunity. Nor did they acknowledge that there had been a blip in the 1980s and again -- and I will come to it later on -- again very recently. The

Health Committee in October 2001 made various recommendations to the Executive. They set up a mechanism for providing financial and other appropriate practical support to all hepatitis C sufferers who had the virus as a result of blood transfusions provided by the NHS to those people at that time. I should say in the process of a Health Committee, apart from our petition to the Parliament, there was another petition relating to a person who got a blood transfusion and ever since, where we differ from perhaps the rest of the Haemophilia Society, we have acted and been supportive to people who got blood transfusions resulting in hepatitis C as they had no umbrella organisation.

THE CHAIRMAN: You mean those were not haemophiliacs?

PHILIP DOLAN: Not haemophiliacs and I will come to examples of that later. The Health Committee made their recommendations, as I have said. This then was followed by -- the minister by this time was now Malcolm Chisholm. He decided to reject her recommendations and set up an expert group under Lord Ross. Lord Ross was formerly the most senior judge in Scotland and distinguished person. The committee consisted of doctors, lawyers, nursing and ethics and various people and myself and the committee continued for a year, with provision that they had to have a preliminary report by the July of -- six months in -- on hepatitis C. The committee's title is a fairly long one but perhaps I should read out what it is:

"To consider circumstances in which financial -- which a financial -- sorry, I will start again -- to consider circumstances in which a system of financial and other support might be available, people who have been harmed by the NHS treatment in Scotland in circumstances where there is unlikely to be liability on the part of the NHS and to apply general principles which are consistent and equitable and transparent to all."

That was a very difficult title to try and remember.

THE CHAIRMAN: The point was that it concentrated on the financial need rather than on the history of the infection?

PHILIP DOLAN: Yes, on the fact that people had been harmed by the NHS but in the legal system people could not get into it.

Again, the committee met for a year and made recommendations, and I will come to them. The recommendations were that an initial lump sum of 10,000 to cover inevitable anxiety, stress and social disadvantage; an additional lump sum of 40,000 to those who developed chronic hepatitis C. In addition, those who subsequently suffered serious deterioration and physical condition because of a hepatitis C infection; for instance, cirrhosis of the liver, cancer and other similar conditions, should be entitled to additional financial support, on an ongoing basis if necessary, as may be assessed by appropriate trust. This financial support should be calculated on the same basis as common law damages, taking account of payments made to the above. Where people who have been beneficiaries of these arrangements are deceased and their death was not due to hepatitis C, the above payments should pass to their executors. Where their death was due to hepatitis C virus, the trust should provide payments to be made to dependent children, spouses, partners, parents as appropriate. Within the appendix, there are full details of that. So these are here in part.

Again, the Health Minister rejected this expert group set up by him and during a TV interview some months later, Lord Ross, which I think was very brave of him, observed it was difficult to understand that there was a problem of finance, given that a building that should have cost £40 million was now costing £400 million. There was no difficulty in finding the money for that and felt that his expert group had been set up as a delaying tactic by the government.

On 29th August 2003, Malcolm Chisholm, the Health Minister, announced that he proposed to make an ex gratia payment to those infected. Those infected with chronic hepatitis C would have received 20,000, an additional payment of 25,000 would be made to those who developed cirrhosis or cancer. No payment would be made to dependents of those who had died prior to 29th August 2003.

THE CHAIRMAN: That was again presumably because they were saying, it will not be retrospective? The cut-off date is the date when the provision was made?

PHILIP DOLAN: We do not know why the 29th because of a committee he had set up was pre-dated that as well and enquiries there. So shortly after that -- after Malcolm Chisholm announcing this, the Westminster Health Minister at that time, John Reid, announced that he would follow the decision of the Scottish Executive. A scheme known as a Skipton Fund -- and I take exception to this because Skipton Fund, for the benefit of those who do not know, is a name of a Department of Health building here in London, there, not a place in Skipton in Yorkshire, not a building society but somewhere which the Department of Health would seem to have hijacked, the scheme at this time, which would not have existed if it had not been for the work of the Scottish Parliament and, I would say, for the work that I personally and a few others did that prompted the government to do so.

THE CHAIRMAN: You say it was set up in July 2004?

PHILIP DOLAN: Yes, the announcement was made in August 2003 but the actual scheme and the Skipton Fund came into being theoretically on 4th July and there was again a caveat that if any person died before -- had died before 2004 and had not registered with Skipton Fund, then they would not get any money. In April 2005, the Health Committee, during the second reading of a bill going through the Scottish Parliament which would allow the Scottish government to make payments into the Skipton Fund, the Health Committee recognised the derisory dates in there and they removed the dates, they removed the dates of 29th August so those who died prior to that date would actually get a payment and they removed the dates of 4th July. However, sadly, on June 2005 the Health Minister at the third reading of the bill then decided to reintroduce the dates -- of 29th August. He was successful by 56 votes to 52 votes there. Now, if just two of Labour or Liberal MSPs who had signed -- who were signatories to the motion in 1999 had voted with their conscience, then it would have been passed and those widows and dependants would have received a payment.

In January 2006, the Health Committee heard evidence from the Scottish Haemophilia Forum and other campaigners and a submission by Frank Maguire(?), who is the legal adviser to the Haemophilia Forum -- this, obviously, is one of the parts of doing it, he provides advice to others free of charge. He himself had been a member of the expert group.

During the discussions various information came out and questions were raised and the Health Minister and his official were unable to answer questions from the MSPs and members of that committee. Some of these were, we recognised, a signed report, which is one of these reports prepared in Scotland by the professions about the management of hepatitis C. We found in that report it was suggested that perhaps 2,000 people who got blood transfusions prior to 1991, had not been traced. The minister and his officials could not answer how they were going to deal with that. Of interest, when the second draft report of that, that 2,000 had disappeared as a figure in the report, but they still exist. During the hearing we also raised questions about the sources of donations of blood and these were obviously questions coming from prisoners. A BBC television programme had not long before that noted the fact that not only were they getting blood from prisoners during this time but it was believed that they were getting blood from American troops based in Scotland. As I understand, they would have been unable to donate blood in America.

There was also a question, as I said earlier, about the protein fraction centre of the blood transfusion service having had these difficulties in the 1970 and the 1980s and the minister in the letter -- and there is a copy of the letter in the paper here to the Health Committee -- he suggests that:

"The deficiencies and improvements required to be addressed had been dealt with by the Scottish Blood Transfusion Service."

That was in a letter dated 20th February. At the meeting which we were talking about in April, sadly for him, the blood fraction unit had been closed down a few weeks beforehand because it had failed to meet the requirements for a medicines inspectorate. The blood fraction unit is completely closed now as from last year.

THE CHAIRMAN: It has not been reopened?

PHILIP DOLAN: Not been reopened, on the basis that it would cost them £20 million to bring it up to standard. Again, there is a copy within the documents of the letter from the Blood Fraction Unit, Professor Franklin, to me, confirming that.

The committee on that date deliberated on information when it met in April and decided that they should have an independent public enquiry. The minister, again in June, wrote back to the Health Committee asking them to change their mind and the committee decided not -- they were not going to change their mind and, in fact, at least one or two of the Labour members of the committee at that time switched over and supported the fact that there should be a public enquiry and that the minister had no right to ask them to change their mind. Perhaps I should say at this moment in time, there is, as you know, within the last week or so, an announcement by the Scottish Executive that the Minister of Health, now an SMP member, Nicholas Surgeon(?) that they propose to hold an independent judicial enquiry but they will await the outcome of this --

THE CHAIRMAN: I think we saw that.

PHILIP DOLAN: GRO-A GRO-A According to the Blood Transfusion Service documents, saved from a shredder in Scotland, in 1984, the following observation was made:

"At present, nearly all virgin, newly treated haemophiliacs become infected with Non-A/Non-B hepatitis, though not usually dramatically severe, but 40 per cent show evidence of infection by hepatitis B. The longer terms effects of such infections in haemophiliacs is not known with certainty because until relative recent years, they had little prospect of living to middle or old age."

GRO-A

In 1991, I became aware of hepatitis C GRO-A

GRO-A

THE CHAIRMAN: We have had quite a bit of evidence on this from Scottish patients.

PHILIP DOLAN: GRO-A

GRO-A

Obviously, one learns the impact of hepatitis on one's physical and social life with the stigma associated with hepatitis C but the assumption is that hepatitis C is something to do with people who have drugs or alcohol or various other problems. And we have a lady who came to one of our meetings who had a blood transfusion and her choice was, she would not go to hospital. She was attending the clinic which was known as a hepatitis C clinic and she did not want to be sitting in that area in case somebody went by and thought she was on drugs or some other activities. The problems of obtaining insurance -- and again, I have enclosed a page out of an insurance application form which classifies people with haemophilia among drug addicts and various other categories who had a different --

What I would like to do now, as I come towards the end, is outline an example of a few people whom we have been involved with. The youngest person with haemophilia, known to be infected, was born in 1986, was first diagnosed and treated in 1987, when, in fact, in England, blood was being heat treated to 80 degrees. Scotland did not heat treat until 1987, to 80 degrees, and, in fact, according to a Blood Transfusion Service and haemophilia doctors, who seemed to have different views, the Blood Transfusion Service did not issue a document to say: take these off-the-shelf and the haemophilia doctors did not do it. That is their argument. The Blood Transfusion Service would suggest that they should have known better and should have taken it off. It could well be for two years or even after that, people are getting Factor VII or 9.

THE CHAIRMAN: Everyone knew was subject to possible infection?

PHILIP DOLAN: And there certainly were lots of documents. Case B is a 30-year old who, like many children during the early 1980s in the west of Scotland, were treated with American Factor VII and infected with HIV and HCV and his parents were told he had received products -- sorry, later on he, in fact, learned a couple of years ago that he got a letter to say that he had received products which had come from a donor with variant CJD. That chap, who is one of our campaigners and being quite ill, stood outside the old Parliament building in Edinburgh most days with his plackards, saying what he thought of MPs and, in fact, became such a known person that the tourist bus going round Edinburgh would say, there is a young man who has been campaigning outside here.

The next one is a 30-year old who learned he had hepatitis C status in 1994 and that is from his doctors but his employers' welfare officer came out to visit him at home when he was off with a bleed and showed him his medical file and in it was a letter from his doctor in 1991 telling his employer that he had hepatitis C, when he, in fact, was not not told until 1974.

THE CHAIRMAN: 1994?

PHILIP DOLAN: 1994. [redacted] is a mild haemophiliac who had never received Factor VII at all up to that point. He had an accident in 1986. He was then given Factor VII and the following morning, his consultant in Edinburgh came round and said that the good news was he was getting better, the bad news was he had a 50 per cent chance of having a virus. It was quite interesting, given that most of us were not told we had a virus and that one single treatment he got hepatitis C from. He has never had any treatment since but he tried to take Interferon and like so many people, have had severe reactions to this.

I have listed various ones here, so you can have it in front of you.

I would want to go to the other group because during the period of campaigning in Scotland, apart from the haemophiliac community, there had been links with people who had been infected as a result of blood transfusions who did not have an umbrella organisation. It is a recognised link, haemophiliac population. It was not until years later that they learned they had been infected. The government statistics suggest about 2,000 people who received transfusions prior to 1991 had not been traced.

[redacted] received a blood transfusion in 1982. About the year 2000 she had become unwell and it was not until 2003 she was told she had hepatitis C. She sexually transmitted it to her husband, who died as a result of hepatitis C and the story of that is attached in the documents here. [redacted] received a blood transfusion following the birth of a baby in 1982 and again, it was not until 2000 that she was told that she had hepatitis C.

[redacted] is a person who made contact with me in December last year. The individual had been in hospital for some routine examination. During the appointment a nurse taking blood received a needlestick injury and according to health and safety regulations, the patient was asked if they would agree to be tested for viruses. The patient was tested and the patient was found to have chronic hepatitis C; the only explanation being that in the mid 1970 and mid 1980s, the individual had had transfusion for operations. This person had never been traced back anywhere but during the period of 1970s and 1980s, the person continued to be a blood donor and again, we had raised with the Health Minister way back, why people had not been traced.

These examples demonstrate the delay informing the recipients of blood transfusion and blood products but also demonstrates how both groups could be linked. The person who received an infected blood transfusion in 1970s was not traced back and continued to be a blood donor. The person's's donation could eventually have been part of a pool of blood which made Factor VII and was then transmitted to people in the pool of blood. How many of these cases exist? We do not know but one is one too many. Suggestions have been made by ministers and other officials it has been suggested that people with haemophilia were aware of a possibility of viruses in their treatment as there were warnings in the packs containing Factor VII. This is a spurious argument, given that today, many people with haemophilia still receive their treatment in hospital and all they ever see is a syringe prepared with Factor VII in it. However, most people will have been been infected long before home treatment was available. In Scotland, a check made by members of centres; there was an argument put up at the Warwickton centre. We have checked every haemophilia centre after that statement was made and nobody found any warnings in treatment rooms, et cetera. And how many of us sitting here, when we get a packet of paracetemol, read the little notice --

THE CHAIRMAN: I always think that things that we get with medication are usually in very small print with a very large number of words and I suspect that most of us do not read them very carefully.

PHILIP DOLAN: This is my concluding part here. In 1999, I commenced my journey to seek an enquiry why so many people with haemophilia have been infected with hepatitis C and other blood viruses. Little did I realise the obstacles and maze I had entered. Several of those who started the journey with me are now dead. Others are quite ill as a result of hepatitis C or the serious side effects after treatment for hepatitis C. GRO-A I believe they GRO-A needed an explanation. GRO-A GRO-A GRO-A Why do medical files and documents go missing? The former Health Minister, Andy~Kerr, in Scotland, stated an enquiry would not get to the truth. Why? Surely he is not suggesting that politicians would not tell the truth. Is he implying that his officials would tell lies? Certainly, the people and their families who are infected will tell the truth because they live with the consequences every day.

THE CHAIRMAN: In fairness, I thought he was saying, everything is already known, there is nothing new for it to find out?

PHILIP DOLAN: In discussions he just said it would not get to the truth. Sometimes I feel that my journey mirrors the obstacles met by Christian in the Pilgrims Progress: into the valley of the shadow of death, the doubting castle in great despair. Perhaps like Christian, I might meet the great heart who overcame great despair and other monsters and bring us to a conclusion. The truth will overcome the years of denial. I would say the government who, over the years, have failed vulnerable groups as a result of NHS treatment sould recognise their denial and what we have suffered.

THE CHAIRMAN: Thank you very much. Mr Dolan. Thank you for making it so clear.

JUDITH WILLETTS: Thank you very much.

THE CHAIRMAN: Shall we let everyone get lunch? Shall we resume at 1.15?

(12.10 pm)

(The luncheon adjournment)

(1.15 pm)

THE CHAIRMAN: Shall we come together?

HAEMOPHILIA SOCIETY UK

MR RODDY MORRISON

RODDY MORRISSON: We have given quite a detailed written submission already and --

THE CHAIRMAN: This one?

RODDY MORRISSON: And I have a shorter statement which I will read through, if I may. That is great.

Okay. I am Roddy Morrison and I have the honour to chair the Haemophilia Society nationally. I take pride in speaking for the society here today GRO-A

GRO-A

GRO-A Firstly, I first pay tribute to Lord Morris, without whose tireless and inspiring efforts we would not be sat in this room today. I would also like to say how grateful we are to you for your understanding and humanity in accepting Lord Morris's invitation to undertake this independent public enquiry which we hope will finally bring closure for our members. The 19th February, when this enquiry was announced, will be remembered as a historic day for us. The enquiry has heard many times already that almost 5,000 people with haemophilia were infected with life threatening viruses through their treatment in the 1970s and early 1980s and just to give an idea of the scale of the disaster, that represents four out of five people with haemophilia at that time.

The numbers themselves do not speak loudly enough on occasion. We have heard testimonies of how these infections have devastated individual lives, families and communities. Worst of all, we have heard about how many of these infections could and should have been prevented. It is the role of a civilised society to prevent disability and if it cannot prevent, then to protect the stricken. The haemophilia community was not protected and the infections were not prevented. This is not a tragedy. It is a preventible disaster. Our submission and copies are available for anyone who wants them at the back, demonstrates a catalogue of delays spanning across two decades. Each one of those delays meant more preventible infection and more lives lost. In 1974, Dr David Owen MP, as he then was, a health minister, announced funding to pursue a policy of self-sufficiency in blood and blood products. We hope that Lord Owen will give evidence to this enquiry himself but our understanding is, that as a doctor himself, he was alarmed by the fact that much imported blood came from the USA, a country with a high incidence of hepatitis. He was concerned that paid donors were being recruited from high risk communities, such as prisoners and people living on skid row. Unfortunately, David Owen moved to the Foreign Office and self-sufficiency was never pursued. The failure to protect an already vulnerable community was not one of resources; it was one of political will. The self-sufficiency alone would not have prevented many hepatitis cases and it is important to note that American products were not the only source of infection but it would largely have prevented the UK from importing the HIV virus, which was not a known threat until 1981. Self sufficiency, combined with the testing of blood donors for hepatitis, would have given a great deal of protection against both viruses. The testing of donors for hepatitis C was not introduced in the UK until September 1991. The government claims that it was the earliest possible time, given the available technology. This is nonsense. Do not just take my word for that. In a landmark court case about infected blood products, Mr Justice Burton ruled in the High Court that a full hepatitis C donor test should have been introduced in March 1990 and that a surrogate test should have been introduced prior to that. Surrogate tests exclude donors with raised liver enzyme levels, a generic symptom of hepatitis. Germany introduced a surrogate test in 1965. It is probably worth repeating 1965, not a couple of years out, it is substantial. And by the mid 1980s, the UK was one of the only countries in the developed world not to have a test in place. Our belief is that self-sufficiency, combined with the introduction of a hepatitis surrogate test, would have prevented most of the infections in the haemophilia community from occurring. Once the problem of HIV infection through blood products came to light in the early 1980s, further dithering meant yet more infections. Critically, we were not told of the risks involved, as you have heard from a number of people already, and therefore, were not empowered to make our own decisions about the treatment that we needed and wanted.

In January 1983, an article in the New England Journal of Medicine warned that blood products were exposed to contamination with Aids. The report recommended consideration of a return to cryo-precipitate, a safer but less sophisticated and convenient treatment than clotting factors. It was accepted within the medical community that newly identified patients, infants under 4 and patients with mild haemophilia -- and there is quite a significant difference between mild and severe haemophilia in these terms, there is more in the actual submission -- they should not be treated with the clotting factors, they should be treated with either cryoprecipitate or DDAVP as a synthetic alternative to clotting factor. For reasons that have never been explained, this recommendation was frequently ignored. Many people who became infected, including little GRO-A, whose parents we heard from at the last hearing, should never have received clotting factor. The LAV virus, later named HIV, was discovered in early 1983. By may 1983, it was known that it could be destroyed by heat treatment. Nevertheless, heat treatment of blood products was not introduced in the UK until 1985. By the summer of 1983, a rudimentary LAV test have been developed. It could not have been used to test individual doors but it could have been used to test one sample from each batch of clotting factor. If the batch was found to be infected, the whole batch could have been discarded and safety maintained. Once again, no screening was introduced until 1985. Despite this, many people with haemophilia were tested for Aids in 1983 and 1984 without their knowledge. Most have reported considerable delays in being informed of the results. This put their spouses at further unnecessary risk. 63

sexual partners are known to have been infected. A similar picture of delay characterises the lack of action taken to prevent the contamination of blood products with Non-A/Non-B hepatitis during this period. I have already referred to surrogate screening, which had been introduced in most other developed countries by the mid 1980s. There were also delays introducing heat treatment. Scandalously, and Phil Dolan touched on this before, the heat treatment to a high enough temperature needed to kill Non-A/Non-B hepatitis was not introduced in Scotland until 1987. 18 months behind England and Wales, where heat treatment was already overdue when it arrived in 1985. In addition, many people report being secretly tested for Non-A/Non-B hepatitis in the 1970s and 80s, but not being told the results until the early 1990s. This denied them the opportunity to take precautions to prevent the spread of infection to friends and family and also to take action to safeguard their liver, such as cutting out alcohol. We have therefore seen that many preventable infections were not prevented.

THE CHAIRMAN: Have you had in feedback as to why the medical profession were in so many cases so reluctant to tell people the results of the test?

RODDY MORRISSON: No, I have not. The feeling I am left with is the medical community were using the knowledge they had but without feeling the need to inform other people. I do not understand what possible reason there could be of not informing people. But when it is set out like this, it just seems so clear it should have been done. I do not understand. If I just summarise; we have outlined seven crucial failures and again, words are important in this. Mistakes, is a word that is used. I do not see them as mistakes. I see them as failures; the failure to deliver self-sufficiency, the failure to implement a surrogate hepatitis test, the failure to restrict the use of clotting factors once the risks became known, the failure to implement HIV screening swiftly, the failure to introduce heat treatment promptly. Delays in informing people of their infections, leading to the avoidable infection of spouses and finally, the delay in introducing a hepatitis C donor test. And I repeat, it is not a tragedy, it is a preventible disaster.

Our submission was based on the very limited information available to us. Although some information has been released under the FOI, thousands of documents have yet to be released. We believe that the government has been selective about what has been released, although of course we do not know what we do not know.

We ask that the inquiry will finally uncover the full truth about what happened. We are lay people and cannot put a figure on the number of lives that would have been saved and infections prevented if it had not been for the seven deadly failures that I have just detailed. And I ask that you will try and do this.

Every couple of years the Haemophilia Society has conducted a needs assessment to try and assess the impact on our community. The results of many of these have been submitted to the enquiry. They show a community coping admirably, in circumstances where ill-health and social stigma are part of day-to-day life. There have some hard lessons for all of us. The Haemophilia Society has certainly learned to be less deferential to doctors and to take their word at face value and we have also learnt how important it is that everyone in the community keeps talking to each other and keeps together.

However, the injustice is palpable; that people who have been infected with life threatening diseases in circumstances which should have been avoided, are forced to live their curtailed and ailing lives in poverty and again, I think some of the points that were made this morning about the benefits situation, et cetera, outline exactly how that is.

We have heard this more powerfully than I could ever convey, from many infected people in the first two days of the hearing and I want to pay tribute to the bravery of all of those who have told their stories. It is far from being an easy thing to do and there are many others whose voices will not be heard directly here and I ask that their stories will be represented by Gareth Lewis at a future hearing.

People living with viruses, as well as haemophilia, a case of disaster heaped on existing disability, if ever there was one, are often denied opportunities and experiences that the rest of us take for granted. If they can overcome discrimination and find work, they are often held back by poor health. Many are caught in the benefits trap. They find it very difficult to access mortgages, pensions and insurance. They cannot travel freely, partly due to the cost of insurance but also because many countries place restrictions on entry for HIV positive people, in particular.

Pressure is put on personal relationships and starting a family in the usual way is impossible. And related to that in part, in the main submission there is a chart that shows how the birth rate for haemophilia has halved between 1987 and the present day. This is directly as a result of people seeing their grandfathers fall dreadfully ill and die.

We ask that having considered the circumstances surrounding the infections, the enquiry team will recommend what assistance should be given to those affected by these viruses. The Irish settlement is a good example that could be followed, particularly because it includes assistance with mortgages, insurance and healthcare, as well as financial settlement.

I would like to finish by talking about where we are today with treatment for people with haemophilia and it is clear that lessons have not been adequately learned by government from the disaster of the 70s and 80s. In the 1990s it became apparent that blood products were potentially infected with VCJD. Yet it took a decade of hard campaigning for the haemophilia community to access recombinant treatment for all. We do not yet know how many people with haemophilia will fall victim to this horrific disease. I do not think we will know for another six or seven years. What we do know is that the worry is constant and that the universal "at risk" status attached to everyone who was treated with British blood products between 1980 and 2001, in itself imposed consequences, such as problems of accessing healthcare and insurance. How can a government in one of the richest countries in the world act in this way. The haemophilia community, already affected by a life threatening condition, already infected en masse with two deadly viruses, was then denied the recommended safe treatment of the time, again on grounds of cost. We therefore have good reason for deep concern about future medical treatment for people with haemophilia. The Department of Health must adopt a more inclusive approach and allow the Haemophilia Society a formal role in setting the policies that affect its members. It is important that we look forward as well as back in this enquiry and ensure that lessons are really learned. We will make a further submission, detailing recommendations for the future. We will be emphasising the need of the affected community for counselling and/or support, as well as making recommendations on consultation and future access to treatment. But it is important that the enquiry first completes its examination of the facts surrounding the contaminated blood disaster. It is crucial that the government participates in full, releasing all papers, sending ministers to attend as witnesses and pledges itself to abide in full by the enquiry's recommendations. Most --

THE CHAIRMAN: I think possibly that is a little optimistic. I have never come across a government before an enquiry has reported, saying: we will implement every one of their recommendations. You must not get too carried away.

RODDY MORRISSON: I will take that in balance but optimism and hope has kept a lot of people going over the years. So we will stick with it. And most importantly, the government must demonstrably learn from the mistakes of the past. It is very easy to pay lip service to a phrase like: "We have learned the lessons from this", and we cannot see the evidence of that and that is what will prevent a disaster like this occurring in the future. Thanks very much for listening.

THE CHAIRMAN: Thank you very much, Mr Morrison. Two questions in my mind: first, have you had discussions with the officials of the department as a society?

RODDY MORRISSON: Over time, extensively.

THE CHAIRMAN: Did you ever address the question of how the products we have been talking about came to be licensed? Or have you seen minutes of the committees that decided?

RODDY MORRISSON: I think we might have some coverage of that. I hold my hands up and say I am not 100 per cent sure, off the top of my head.

THE CHAIRMAN: I would be grateful for any information we can have on that but it seems to me to go almost to the root of what happened.

RODDY MORRISSON: Absolutely.

UNKNOWN SPEAKER: Haydn and Andrew March will talk about that later on when they give their submission on behalf of tainted blood.

THE CHAIRMAN: The other question that was in my mind. You have said the Society should have a formal role in decision-making in the future. Would you like to develop that in a little more detail?

RODDY MORRISSON: I will come back to that in the second submission that we make, if we can. That is something we are working up at the moment and we are going to work on it with the Haemophilia Alliance, which is a joint group between the medical community and the patients as well. We will be looking particularly to the experience in Ireland where, off the back of the activity there, the Irish haemophilia community have a very strong voice and certain statutory bodies cannot meet unless the patients are represented.

THE CHAIRMAN: I see. But hopefully, we will get that before we get round to reporting. I was not sure.

RODDY MORRISSON: No, indeed.

THE CHAIRMAN: Yes, thank you.

RODDY MORRISSON: We are working on it now.

THE CHAIRMAN: Thank you.

JUDITH WILLETTS: I am very interested in what other countries were doing prior to any kind of hepatitis C testing that was done here. I am interested in this ruling by Mr Justice Burton that a full hepatitis C donor test should have been introduced in March 1990. It was actually introduced in 1991 here, was it not?

RODDY MORRISSON: September 1991, yes.

JUDITH WILLETTS: And the virus was identified formally as Hep C in 1989, so what was happening in Germany and in the other countries where they were successfully using a surrogate test that was testing for raised liver enzyme levels, which would have screened out anyone with that. So any potential --

RODDY MORRISSON: Absolutely, and I think that would probably have stopped quite a few of the hepatitis B incidents that happened earlier on.

JUDITH WILLETTS: Is there direct signs of the evidence of that?

RODDY MORRISSON: Of?

JUDITH WILLETTS: Of what it would have prevented?

RODDY MORRISSON: I will take that away and check.

JUDITH WILLETTS: Do you also have statistics of people suffering from haemophilia and any kind of viruses that they were getting or not getting? Do we have statistics on the health, if you like, of people in other countries who were obviously having to be in receipt of some sort of blood or blood products?

RODDY MORRISSON: Again, I will take that away if I can. I
    should be able to get quite a lot of that from the World
    Federation of Haemophilia and the data and statistics
    that they have.

JUDITH WILLETTS: That would be very helpful.

RODDY MORRISSON: Yes, of course.

JUDITH WILLETTS: May I ask another question?

THE CHAIRMAN: Yes, please do.

JUDITH WILLETTS: In terms of the recombinant treatment --
    I know there is an issue about access -- is there any
    kind of postcode lottery or is it down to which hospital
    you attend? Can you tell me a bit more about that?

RODDY MORRISSON: Now?

JUDITH WILLETTS: Now, actually.

RODDY MORRISSON: Now; my understanding is that there is
    access to recombinant treatment for Factor VII.

JUDITH WILLETTS: For all?

RODDY MORRISSON: Yes.

JUDITH WILLETTS: When would that have started, that access
    for all?

RODDY MORRISSON: Last year.

JUDITH WILLETTS: It is as recently as that.

UNKNOWN SPEAKER: If I might add, it was phased in over
    three years according to age because children got it
    first and the older people have been --

RODDY MORRISSON: There was a postcode lottery before that, whereby the more enlightened parts of the United Kingdom, Scotland and Wales, had introduced this. So there was a lottery at that point. You certainly got many questions about; if a Scottish student was moving to England to study, how would they protect their treatment. Or if you were denied treatment coming off a trial, say, of recombinant, there was actually quite a strong feeling to move your family back to Scotland or Wales if you came from there. I certainly considered that.

THE CHAIRMAN: But we have been told that each hospital could make its own decisions about the medication which it ordered. So would it depend to some extent on where the hospital placed its order and how it was done?

RODDY MORRISSON: Yes, I cannot remember the precise details but before there was a national contract, I think there would have been some element of that and I think as well, it would be tremendously beneficial to have some of the clinicians concerned sitting where I am sitting.

THE CHAIRMAN: I hope we can do that.

RODDY MORRISSON: Me too.

THE CHAIRMAN: I am sorry, we cannot turn this into a public meeting. We must keep the evidence in order.

LORD TURNBERG: That is very clear.

THE CHAIRMAN: Thank you very much.

VIJAY MEHAN: Can I ask a little bit about what the Haemophilia Society does to assist its members and a little bit more about the Haemophilia Society itself and what it has done with respect to campaigning.

RODDY MORRISSON: Yes, there is a long history of campaigning, which is set out in the full submission. We are working very closely with Lord Morris and other parliamentarians and we have worked hard to get an all party parliamentary group in place, which has been tremendously beneficial as well, very, very helpful. We are very fortunate to have that.

In terms of the services we provide, we have a long wish list of services we want to provide and we are constrained, as most charities are, by funding but we run projects for youth; some of the growth areas we are looking at now impacts on older haemophiliacs, because they are living longer than was expected once upon a time. We would love to do more into direct support for the haemophiliacs affected by the viruses directly. We used to have dedicated workers both for HIV and Hepatitis C but the funding does not allow us to do that at the moment and again, section 64 funding was mentioned by others this morning. We used to have much higher government funding than we do now and in fact, it has been announced that it is going to be completely phased out to nil over the course of the next two or three years. So there will be no Department of Health funding for the Society at all going forward, which means that we spend our time and energy fundraising.

LORD TURNBERG: We have heard many patients who have suffered very badly being very critical of the medical care at the time. Presumably, most haemophiliacs now are seeing a doctor or doctors in the haemophilia clinic?

RODDY MORRISSON: Yes.

LORD TURNBERG: What are relationships like now? How has it affected relationships --

RODDY MORRISSON: Relationships specifically?

LORD TURNBERG: Between the doctors that you are seeing now and the haemophilia patients. Is it one of armed truce?

RODDY MORRISSON: Yes, I think the fact that we are doing this now, one or two decades later than it should have been done, is probably bringing some of that to the surface again. So it is harder. But I hope that that does not impact on individual patient/doctor relationships. I am sure other people have things to say on that. We know that we need to work together very closely with the medical community because we cannot progress the (inaudible) that we want without them. We need to work hand in glove going forward and the Haemophilia Alliance is very, very important within that, which is why we are keen to work with the Alliance to -- when we put flesh on the bones for some of the recommendations we want to make about statutory representation, et cetera, we want to do that with the medical community in a joined up way.

LORD TURNBERG: Did you say we were going to hear more from the Alliance?

RODDY MORRISSON: Not specifically from the Alliance but I am going to work with the Alliance to make sure that the recommendations that we put forward in our second submission, they have some input into that as well. Although I am sure some of the people from the Alliance would be happy to attend if asked, in terms of the doctors, I hope.

LORD TURNBERG: We have seen the doctors.

RODDY MORRISSON: Good.

THE CHAIRMAN: Thank you very much, Mr Morrison.

RODDY MORRISSON: Thank you.

TAINTED BLOOD INFO

HAYDN LEWIS AND ANDREW MARCH

THE CHAIRMAN: Mr Lewis and Mr March, thank you very much for coming. We await your presentation.

HAYDN LEWIS: Thank you for asking us.

THE CHAIRMAN: Thank you for providing us with the notes beforehand.

HAYDN LEWIS: Well, I am going to start off this by kindly asking everybody to spare a few thoughts for all the people that actually are not able to attend here, through the fact that they have passed away and hopefully encourage and just to state that we have attended and hope that we can represent the people who remain and give them confidence that the closure that we all desire is not too far down the road. Thank you.

I am now going to read a little introduction as to how tainted blood evolved, if you wish. So here goes.

Tainted blood is a concept formed primarily out of the two things; firstly, as you know, there was a very large, real need amongst our community to seek answers as to why their infections had happened. Why so many people had their lives and those of their loved ones destroyed and taken away through this. And secondly, in around April, May last year, our plight was once again brought under the media spotlight where people affected by haemophilia and HIV and hepatitis C and others as well, renewed calls for a public enquiry and proper compensation. At that time there was significant discussions occurring on the MacFarlane Trust bulletin board regarding coordinating a campaign across the country. Now, in order to mark this huge media interest that we were enjoying, a small group of us decided to take the initiative and the concept of Tainted Blood was born and formed into a website. At the time, we also hoped that all past and present campaign groups, who we sincerely thank for all the efforts if they have supported us in the past and may support us in the present, would see this media format as a tool. We all should embrace and use to further the agenda of closure for all infected and affected persons in the UK population.

Tainted Blood would like to thank firstly Lord Morris and the Haemophilia Society and all the campaign groups, whatever title they wish to be known as, for their determined "dog with a bone" attitude over the many years this issue has remained unresolved in the eyes of the haemophiliac community. We would also like to thank Lord Archer and his panel members for the time they give on a voluntary basis to this process.

We can both, that is Andrew and myself, place on record that as infected haemophiliacs, one of whom has submitted a personal application to be witness at this enquiry in a personal capacity, had no consultation concerning the title that we actually represent, Tainted Blood.info, which have been given to represent as witnesses. This is decided by the enquiry organisers and we thank them for that chance. We hope the mandated members of Tainted Blood will forgive us for not involving them in this decision. However, it is something we both feel will allow us to debate the subject matter at a level which might help clear the muddy waters which Lord Archer has to clarify. Sadly, this decision is an example of many choices in life the infected and affected have had taken away from them. The enquiry has given a platform to debate and record the facts in public and we at Tainted Blood welcome this process but if ever an issue needed a public debate, I can think of none more worthy.

We also, on behalf of Tainted Blood, would like to publicly commend Lord Archer on accepting this challenge. It will take someone of great courage to publicly state what has been so unpalatable and embarrassing for the government to speak of publicly: Can the inquiry panel explain to the public why government legal advisers felt the need to use Crown immunity to exclude themselves from any liability, for instance, first, with regard to the charge of neglect, which is the only conclusion one can make when you read the inspector's report on the facility at Elstree. Once again, government used the same defence to the charge of duty of care during the HIV litigation; why use it?

In fact, by doing so, Tainted Blood would suggest they accepted their liability. Whatever route it came, commercial or UK, they are all involved in the systematic failure by Parliament and the public bodies they are responsible for and accountable to. It may help if the enquiry study a model within swimming distance of this room, southern Ireland. They had the common sense to see to see that this legal conundrum was and never should have been the responsibility of the victims to prove which product carried the infection. It was a matter of agreeing between those accused how much each was responsible for this patient treatment and furthermore, a public health catastrophe.

Then, with regard to the policy points, we would like to open up for debate with the inquiry panel, hopefully, points including from the accusations document and other important issues with regard to medical ethics, government influence over legal process and also government economic agenda affecting best and safest treatment and care of patients, the risk to the general public from any blood born infection. We have clearly named some items of discussion that we would like to discuss with the panel and we would hope that the panel would actually suggest the ones that they deem to be needing clarification.

So, I am going to hand you over to my colleague how, Andrew, to talk about the aims of Tainted Blood and formally present the accusations document.

ANDREW MARCH: Hello. The aims of Tainted Blood are quite broad, in the sense that we want a solution to be something that is totally inclusive. First, to achieve closure on this. So that is inclusive of a broad spectrum of people and Tainted Blood in its fullest sense. We want a public query -- that is emanating from the government -- surrounding the events that led to thousands of British haemophiliacs infected with HIV and Hepatitis C. We would also like proper compensation and we say that because there has been all sorts of misnomers of -- references to compensation, when it has actually been both ex gratia and no fault compensation. So we feel there has never been proper compensation for the victims and families of those who have died and that is something else that is one of our key aims. We have mandated members, around 249 at the last count.

THE CHAIRMAN: 249?

ANDREW MARCH: Yes.

THE CHAIRMAN: We had it here just 229?

ANDREW MARCH: It is a mistake. We are a campaign group and a support group. Our support role has increased as we have become more publicly visible through the media attention and through the website. We have had to supervise lots of enquiries from people who might not have otherwise approached Tainted Blood for support and identifying their needs.

We have an elected chairman, a secretary and a treasurer. We are not a direct action group. We prefer an academic approach, lobbying, and at most, we would describe ourselves as a pressure group and by far the most brave thing we have done is probably creating the accusations document and disseminating it.

HAYDN LEWIS: Can I make a point? The mandated members were created by the database that the MacFarlane Trust holds and we asked the MacFarlane Trust to mail to all registrants to see if they were willing for us to represent them as Tainted Brood and we have received the amount that you have recorded. But there is another database within the MacFarlane Trust and there are over 300 widows, whom the MacFarlane Trust do not seem to accept that they now meet the criteria that the trust is set to attain; one is helping those infected and affected. I would suggest the 300 widows no longer in contact with the trust are just as applicable for their attention but sadly, that would only come about if they approached the trust and also the trust would not allow us to write to them through the database that they hold. This may have been through reasons of their being a charity but I think it was more to do -- it may have created an additional workload for the trust with the limited funds that they have, obviously, to distribute amongst the registrants that are still registered with the trust.

The matter of the widow being disregarded, as of any interest, when their partner passes away, I find a little bit -- well, uncompassionate, for want of a better word. To suggest that that widow can just carry on with her life after six months of their partner passing away; they may have spent 15 or 20 years looking after that partner and lost a lot of income -- I think you have heard from other witnesses suggesting the amounts that they would have actually lost --

THE CHAIRMAN: I think we have that clearly in mind. It may be that the trust is not at the moment concerned with the fact that it was set up to deal with the particular beneficiaries the government had in mind when it established the trust. It may be no more than that, I do not know.

HAYDN LEWIS: It was set up to maintain the needs of the infected and affected, which remains as it does today.

JUDITH WILLETTS: They support 200 unaffected widows, we were told earlier on today --

LORD TURNBERG: 270.

HAYDN LEWIS: Those are still non-dependants. Obviously, they do support widows.

JUDITH WILLETTS: You say there are a lot whom they do not support?

HAYDN LEWIS: Over 300, as it happens: do you want to formally present -- shall I carry on with that for the time being?

ANDREW MARCH: Yes.

HAYDN LEWIS: We would like to formally present the accusations document so it is publicly recorded and we would kindly ask the panel whether they have received anything that substantiates or questions, contrary to the content of the accusations document, so we can in some way accept that the content is factual and not discuss the content in some detail because if the panel accept that it is correct, and we are writing what we have stated as an accusation, then I feel that it is an easy job for yourselves to actually record that these matters did take place and it has been factually proven.

THE CHAIRMAN: We cannot predict at this stage what evidence we will get at later stages.

HAYDN LEWIS: No, of course. Would you agree though --

THE CHAIRMAN: We will certainly have it in mind and if it is challenged, I think we can come back to you --

HAYDN LEWIS: I would appreciate that because obviously we would wish to be party to that information.

JUDITH WILLETTS: We have had very helpful information on timelines, you know, the chronology of things, which has -- which is factual. So I am happy that we have got the right information on that.

HAYDN LEWIS: I am glad you mentioned the timeline. I wondered whether yourselves or any of the panel have actually read the timeline on Tainted Blood because I think it does actually give you a very clear picture.

JUDITH WILLETTS: We have had -- I certainly I have read probably three or four, now, comprehensive chronologies.

HAYDN LEWIS: I do understand it is very long.

JUDITH WILLETTS: That seemed to match up. It seems to contain the right facts. There is a lot of cross referencing to be done.

HAYDN LEWIS: Without having to go around the subject, I think that the timeline from Tainted Blood is by far the most extensive timeline that anybody has ever written, or read for that matter, with helpful little comments.

JUDITH WILLETTS: Thank you.

HAYDN LEWIS: I am going to turn the page now, where are we? I am going to continue with this for the time being but I am going to pass you over to my colleague. Just to say that we did not produce the accused document to be confrontational or inflammatory but we just felt that, actually, unless we made some statement publicly, we were never going to generate any public debate and sometimes, you know, words need to be stated and, as much as they might be uncomfortable and a bit accusational, as the document suggests, it was only by way of actually encouraging to get a debate on that level, if you want, on the topics that we have included in the document. So I am going to let Andrew speak a little bit about that.

ANDREW MARCH: The first thing I would like to say is that the accusations document was actually in the pipeline and being created prior to the inception of this enquiry, which I was quite pleased about but of course when the enquiry was announced, we found ourselves in a state of flux but we decided to continue with it in case it became useful.

THE CHAIRMAN: It can certainly provide part of our agenda.

ANDREW MARCH: Earlier this year there had been information coming out of the government via freedom of information. We suddenly found ourselves with a considerable amount of documentation and we basically designed a system for reading it, a three tier system of different groups of people reading it and filtering for the most helpful material. We then decided to -- somebody suggested to us, a helpful friend, it was time to lay accusations, and the French "J'accuse" document of the Dreyfus affair was referred to, and I thought that was a wonderful idea. So we decided to make it "We accuse", as opposed to "I accuse", and we went from there and basically crafted eight main accusations of -- that covered the timespan involved and from that we built evidence around them to elucidate and elaborate on further in the document.

We also wanted it to be something that would create a debate, that would hopefully invite a response, which we have not really had. We have not had responses.

HAYDN LEWIS: Which I am pleased. We were waiting to be sued. So maybe their silence suggests something as well.

THE CHAIRMAN: We cannot be responsible for the responses you have had from the government.

HAYDN LEWIS: We have not had any.

THE CHAIRMAN: We cannot be responsible for responses you have not had.

HAYDN LEWIS: I think the silence speaks volumes.

ANDREW MARCH: I would like to talk about "displacements with responsibility". This is a phrase which we crafted for this point, which -- we feel it is unacceptable that individuals that are actually affected and infected are having to become researchers, full-time campaigners. We just feel that the very victims are having to untangle this mess and try to determine how this systematic failure has actually occurred. I came to London as a student to study music at the Royal College of Music on a four-year degree and I feel that is a vocation, it chose me, and it is something that I should be doing because not everybody has that gift. And yet I find myself unable to compose because I just cannot allow this situation with the contaminated blood catastrophe to go unchecked; it needs to be sorted out. And I cannot return to my career and nurture it until I know what happened. There are too many questions. Before, I had the bliss of ignorance and just being able to write and study but, as soon as I realised that things did not quite add up, I needed to become a campaigner and to sort this out.

HAYDN LEWIS: That is a very good example of the fact that we were all at different ages when the infections occurred, and the younger of the community have grown up and educated themselves to the history behind this and are just as shocked as the older community were at the time.

But it should be a poignant reminder to government and anyone who is trying to sort this out that it will not go away because my sons will pick up the flag, and in any battle, if you want to use that term, when somebody falls, somebody else picks up the flag and carries on with that agenda. I hope that Lord Archer actually does bring closure because I think we are in for a long road otherwise because it is not going to go away.

THE CHAIRMAN: We are very impressed with the amount of work and research that members of the community have carried out on this.

HAYDN LEWIS: Thank you.

We can pick up on any of the points that we have suggested in our presentation and I will speak at great length on any that you would suggest need clarifying. So maybe it might be a good time for me to look at the points that we have suggested we need to talk about and, if you have any questions about any specific point, we would be more than willing to answer, but if you want me to continue with a discussion about life support therapy, which is the next point, we are more than willing to continue.

THE CHAIRMAN: I do not know whether I can speak for my colleagues but I think what you have done is set out a vast number of questions which call for answers and I do not think that this is the stage for us to question you. I think what it probably indicates is that we should question other people.

HAYDN LEWIS: I think I was more implying that, if there is anything that you still feel ignorant about --

THE CHAIRMAN: Most certainly.

HAYDN LEWIS: I did not mean that disrespectfully.

THE CHAIRMAN: Quite right.

HAYDN LEWIS: Shall I carry on?

THE CHAIRMAN: Yes, please.

HAYDN LEWIS: I think the best way to actually try and explain my perception of life support therapy, which is an (inaudible) statement that is meant to preserve life, and save life -- when the first commercial products, for instance, came into the country, they came in through an ethics committee and were allowed into the country on a research basis, either on a named patient basis or a clinical trial basis but one of the fundamental hurdles that we needed to get over was to convince an ethics committee that they were for life support therapy. Now, I would have to concede that in a severe haemophilia, then there were many occasions where this was necessary as a treatment, for example, if a member of the public needed a pint of blood or was going to die then there are not many choices there. You take the risks and you accept the consequences but the scenario that unfolded was that the research needed perhaps previous haemophilia patients. So obviously at some stage you are going to run out of them and then you need to start using the mild haemophiliacs. I would suggest that life support therapy was not something that they could use as a reason for giving that product; an example being in 1974 at that stage I had never received any commercial product. I had predominantly only been treated with cryoprecipitate. I started by profession as a self-employed carpenter which suggests that I was not very concerned about bleeding to death. Then I carried on doing that until unfortunately the HIV took over hence the consequences of me not being able to continue with that profession. But going back to 1974 no commercial products I had received up until then. I was on holiday with my then to be wife and attended a hospital in Cornwall where I was given a treatment unknown to me at the time to be a commercial product, without any consultation whatsoever with myself and I kindly thanked him for giving it to me. In hindsight I wish I had not but it suggests that if it was a commercial product, then it was most certainly on some kind of trial because the MRHA data that I have asked for and received suggests that there was no product licences pre-1976. So the product that I was given was definitely given under the heading of either a named patient or a clinical trial. I would suggest that that needs to be discussed the patient, which it never was. And just to emphasise the life support therapy issue, I do not perceive that my life was in threat at all at that time. I had kicked my big toe, rather painful but certainly nothing that I could not have attained by just going home and sticking my foot in a cold bath of water or something. I suggest that the treatment was given not under the premise that it was a life threatening situation in any shape or form and I would suggest that many mild haemophiliacs experience the same procedure. The only reason I was given that product, I might suggest, was up until then I had not received any commercial products so I met the criteria at the age of 17, which is rather unique I suppose, of being --

THE CHAIRMAN: What they called a pup.

HAYDN LEWIS: Yes, and in my notes that I have now been made party to, the records shows the treatment being given but there is no actual mention of the reasons why it was given, for what ailment or what, you know, trauma had occurred, only a reference to the organisation or whatever they are called, public body, and the name of the gentleman who was actually doing research at the time. So it suggests to me that the reason I was given that product was purely to attain some kind of information back from the recipient to the doctor, which I would suggest -- well, it goes without saying, was illegal. But that is for you to decide, not for me to suggest, I suppose.

So the premise of life support therapy and the bringing in of these products, I am not naive enough to realise that any product has a threat and there is a search stage where the medical profession need to assess its effectiveness and its safety and so forth but that does not exonerate them in any shape or form unless they communicate with the patients and gain consent. To date I have never seen any consent form in any patient records that I have ever looked through, my own included, and I would suggest that maybe it might be worthwhile the Inquiry asking the medical profession: can they provide any? In the recent Newsnight programme an eminent haematologist -- I will not name him but I am sure you will get his name from somewhere -- suggested that he was not quite sure whether the consent was gained verbally or in a written form. Seeing as he is still alive, maybe it might be a good idea to just ask him if he can provide evidence to substantiate that because it clearly shows that in many cases the products were given not under the premise of a life support therapy, just one that was going to help the medical profession work out whether the product was actually safe or not.

I do not think I need to actually elaborate too much on that --

THE CHAIRMAN: I think we have grasped that.

HAYDN LEWIS: The point is that this was -- this happened, and unfortunately I think the consequences were that many infections occurred. Also at the time -- I do not think the medical profession --

LORD TURNBERG: I think you make a very important point about the difference between severe haemophiliacs and the milder form because there is a risk/benefit ratio as you suggested, with any treatment, and you take greater risk the more severe the likelihood of someone dying or being severely incapacitated. So the less severe the illness, the smaller the risk has to be and I think that is the important point which may not have been recognised at the time. I think a lot of this was not recognised at the time. I used the term "recently" there. I think the haematologist -- and if you think of haemophilia being as a genetic condition, they were very maternal. They knew the families, they knew the generations and they traced back the generations.

Myself had uncles from previous generations who passed away of course through this, but it did build up this fairly sort of close family community, if you want, within each and every hospital in Britain, and -- I do not want to describe it as a Mr Chips attitude, where he looked on us as Chippy's children, if you want, which does not seem to sit well with looking on that as researching with his children. It is a bit uncomfortable. I think their intentions were genuine but I think they lost the plot slightly with their endeavours to research the matter and they slightly detached themselves from the personal concept of it. I do not particularly want to be disrespectful but they needed to look on us as patients not pieces of interest. I cannot think of a nicer way to put it really. I was going to use the word "meat".

ANDREW MARCH: Could I lead on to the named patient basis, which you will find on page 7 under point 11.

THE CHAIRMAN: Of the big document? Of this one?

ANDREW MARCH: Yes. I would like to talk about this because here we have pharmaceutical companies who need to get their product used, their unlicensed product, and in order to do that there are various ways available to them and one of them is the named patient basis. In order to have their product evaluated, it needs to be distributed and included in the human clinical trials in order to become eventually licenced. This system enables physicians to prescribe unlicensed medicines to a specific patient who is named and recorded.

A discussion is supposed to take place where the prescribing doctor informs the patient of the improvement benefits and that there might actually be risks. To my recollection I do not ever recall this and certainly being very younger at the possible time of infection, nine or ten years old, I certainly do not recall it. So then I have to ask my parents who also do not recall a discussion of this type. So I would suggest that this needs to be looked into. We certainly need to look at how the doctor can protect themselves against liability and yet they can still act with incompetence in prescribing a drug.

THE CHAIRMAN: You say they can protect themselves against liabilities; presumably by observing these rules?

ANDREW MARCH: Yes.

THE CHAIRMAN: If they do not observe the rules then presumably they are not protected.

HAYDN LEWIS: Andrew has led me nicely -- going back to the life support therapy issue. The products were given, predominantly British products at the time, and the understanding and the good relationship between some of your (inaudible) volunteering a pint of blood slightly exonerated them from any consequences of what it may have contained, because it was voluntarily given, and the British system is a marvellous system where always, if there was a need for blood in any conflict in history, they always came to attention and actually provided the blood.

But, because it was given altruistically, there was no liability to that donor and also it exonerated the doctor who used that product and that is fine and well and the recipient of those products were kindly grateful for that donation of blood but I think when the doctors are actually stepped over the line and imported, privately I might say -- and that is where we need to clarify some matters about how these products came into the country from commercial companies. They were purchased predominantly by consultants in the hematology department, they were not purchased through the NHS, and also the minute that you purchase a product commercially, you cannot expect the same insurance cover as you would from a British product given altruistically. So I would suggest that crown immunity, when it was used, actually was invalid because the crown immunity was meant and perceived to cover you for the prescription of a voluntarily donated pint of blood given freely. It should not and never was intended to cover you for giving a private commodity purchased, and gained profit for, the company that provided it.

JUDITH WILLETTS: So you are saying individual consultants took decisions about -- they basically had purchasing power to go to --

HAYDN LEWIS: The NHS was --

JUDITH WILLETTS: This is different from what we were told before.

THE CHAIRMAN: We had evidence about this from the officials if you remember.

JUDITH WILLETTS: I thought this was different.

LORD TURNBERG: It is very unlikely that consultants can buy it themselves.

THE CHAIRMAN: Certainly unlikely.

HAYDN LEWIS: I would suggest that actually --

LORD TURNBERG: We were actually told --

HAYDN LEWIS: I will try and clarify that.

THE CHAIRMAN: Just a minute. We were told that if a consultant went, for example to Singapore and purchased some and brought it back in his pocket he was not committing any offence and he could use it.

HAYDN LEWIS: Okay. I can see this really needs clarifying. Right. When the NHS evolved and Aneurin Bevan struggled to get the consultants on board and he had to make a lot of concessions and one of them was that consultants actually run the NHS. They handed in their receipts at the end of every year and the Chancellor of the Exchequer paid up duly and it was a constant thorn in the back of the government that you were never going to nationalise the National Health Service because you cannot control the budget and so it should be that way also because how can you predict the budget for the unpredictable health of the nation. So targets and everything else were not really an item of consideration but, predominantly because the consultant was in control of his budget and he was freely given that budget because his underlying concerns were one of patient care, not one of running a department within a limited target or within a limited budget, so they purchased these products, or most of them actually on the trial basis were given freely by the commercial companies. It is like a sprat to catch a mackerel: start the patient on this and then he must continue with it. Anyway, so in 1974 when Harold Wilson decided that he really needed to pull in the reins on the budget that the NHS was running out of control with, suddenly chains, and had an reorganisation of the NHS in 1974. That pre-empted an already premise and agenda by consultants of getting all haemophiliacs on home treatment because it was cheaper for the NHS. A mild haemophiliac might spend two weeks, four weeks in a hospital bed, not particularly unwell. He has a really swollen knee which he cannot walk on and the treatment he was receiving, cryoprecipitate, had to be administered in the hospital. There are some exceptions and some doctors allowed haemophiliacs to be treated at home but the point I am making: when the organisation of the NHS occurred in 1974 it took the control of what the budget was away from consultants which also then meant that the health authorities who were then given the control of that budget were not that happy about having to pay consultants for commercial products that they were well aware were ten times more dangerous with regard to hepatitis C. So the budget and the outlay that the consultants had incurred meant that they were not getting the amount back from the Department of Health for the purchasing of that product. So that explains in some way, I think, that these products were not actually -- they were brought in privately by consultants and it was a way also of actually generating income, if you want, for other hematology matters and the budget was not just to attain the treatment of haemophilia, there were lots of other hematology conditions. And to provide us with a product which they would be given rather cheaply, I would suggest, and also the economics of how much it costs to keep a patient in a hospital bed for a month in contradiction to sending that patient home and being able to treat yourself at home, meant that the products did and were cost-effective. However much they might have been costing, it was certainly a lot cheaper than keeping a patient in a bed for a fortnight and all that that incurred to facilitate that.

One of these quandaries that you seem to not have quite sort of touched is how suddenly, right, with this target set in 1974 by Lord Owen and the department, who were meant to provide that product. If you go back to pre-concentrates, there were round about 2,000 haemophiliacs being treated with cryoprecipitate in 1973, 1974. Within the space of two years the demand for that doubled. Now that was not because there was a certain population boom in the haemophilia world. There may have been an increase in identified cases but it pre-dominantly came about because of consultants encouraging us to use the products more freely at home to pre-empt a bleed not happening and that would be all fine and dandy if the product was 100 per cent safe but I would suggest it was rather naive of them to suggest that we take the product freely with the then known threat of hepatitis. I can only speak personally obviously but I never had any perception that hepatitis was a life threatening condition and not really had much knowledge of hepatitis even after HIV came about. Because my, in my youth, my only sort of recollection of hepatitis was post-transfusion hepatitis, where I think I had a bout of it when I got hepatitis B in 1968. I went yellow for a fortnight, was rather unwell but not particularly at death's door, if you want. So my understanding of the threat, as far as hepatitis was concerned, whether it was A, B, C, D or whatever, was one that I would probably be unwell for a fortnight, and go rather yellow but I would get better and I would be fine. But I did not have this sort of education that it was something that could kill you, unfortunately.

THE CHAIRMAN: Our evidence has been that it was not widely known -- first of all what hepatitis C was and secondly how serious it was.

HAYDN LEWIS: It is like anything else in the medical world, until you can categorically say that it is not that dangerous then you should always err on the side of caution and treat it as a worst case scenario. I think it was rather naive on the strength of what they knew hepatitis A and what they knew hepatitis B could do, to assume on the strength of actually only about 18 months of research, when it was discovered in 1972, that it was not something that was going to be a big issue in the haemophilia world and certainly probably something that would be for future governments to address because in 20 or 30 years' time they may start having problems with their livers and so forth. Whereas the same with the government's attitude, if you want, they only really need to be proactive for what is going to happen in their tenure of four years unless they wanted to be re-elected. Their budget is somewhat -- rather than be at the forefront to invest for the future, and a great example is the Life Resources facility that was bought by the British government to accommodate the threat from VCJD. They spent £78 million to secure plasma for the British population by buying Life Resources in America. Life Resources was set up in 1975 to accommodate the production and the fractionation of plasma into Factor VIII because they could see the profit that could be gained from that process. I really wish that Lord Owen had been provided with the money in 1974 to accommodate that process because it would have been a very profitable business, a business run within the NHS, but one that actually incurred a lot of revenue for the NHS and one that probably would have made the treatment of haemophilia self-sufficient in itself, and actually generated profit to plough back into the NHS for treatment and care and it is a constant problem to myself: why did the government actually perceive that private money is more effective than state money. Why did government perceive?

THE CHAIRMAN: That is going a little wide.

HAYDN LEWIS: I can broaden it out as much as you like, they have looked at the NHS as a ball and chain in the last 50 years. Why could we not have looked upon it as Aneurin Bevan intended: a place of excellence, a place of research and study that would be the envy of the world, where there would never be a need for BUPA.

THE CHAIRMAN: We cannot investigate into that.

HAYDN LEWIS: No, pick anyone from 10 and we will discuss it with you.

JUDITH WILLETTS: What I think is particularly helpful is that reading what you have provided for us is obviously going to help with some of the perhaps quite probing and detailed questions that we need to ask of other people and for that I am very grateful. I am also quite interested in what you think about what your concerns are about the danger of history being repeated, if I can put it that way. Would you like to say a bit about that?

HAYDN LEWIS: This stems predominantly from the preliminary responses we have had from government over the past

20 years where an inquiry is now needed because lessons have been learnt. And I see examples of lessons in the NHS that have not been learnt. There is a classic one that has just occurred recently which my colleague is going to try and elucidate.

THE CHAIRMAN: Yes, Mr March.

ANDREW MARCH: I would like to talk about variant CJD and the threat of history repeating itself if we fail to learn lessons that could be learnt. This is page 9. This has come out of recent difficulties of discovering documents which suggest there has been secretive testing around the time -- possibly more than one occasion -- of hepatitis C identification, which is actually a subjective debate in itself but there is a discrepancy between 1987 and 1989. The doctors -- the medical profession and government in the UK -- seem to go with the World Health Organisation's decree of having been identified and isolated in 1989. Tainted Blood recently wrote to the CMO of a company that makes tests in America, who actually vouched for a patent being established in 1987 in the UK and Europe for the identification, isolation and cloning of hepatitis C. Based on this, I would like to talk about variant CJD because there is this problem of we are awaiting a test and no one would deny there is an urgent need for that.

Persons with haemophilia have been anxiously awaiting the arrival of an accurate, reliable, variant CJD blood test since the BPL product recall and notification exercises of September 2004. In fact haemophiliacs have been living if fear of variant CJD from an as far back as January 2001 and possibly earlier when we received our first at-risk letters. We know that there are new blood tests as I have said already, and that different companies are making them. The Shouon (?) Corporation reported that they had developed a prototype prion essaye (?) with a very high sensitivity and specificity for screening variant CJD in blood and blood products. Then in February of this year a Canadian company, Amerfix~(?) Life Sciences, announced that it was presented first time results for their prototype commercial blood test for the diagnosis of variant CJD and there are other laboratories. There are other laboratories, at least seven, currently being subjected to a blinded panel at NIBS (?). That is probably to do with validation of these tests, which is currently underway. Now, I am suggesting that this research is much further on than, certainly that our consultants have led us to believe. I tried to broach the subject with my consultant recently and I got stone-walled and basically told that there is no test. Go away and be quiet. I would much rather a situation where we are included in the consultation process, with regular updates of where they are with these tests and certainly if there is any possibility at all that retrospective frozen blood samples or sera of haemophiliacs are being used to validate these tests because that is just unacceptable.

HAYDN LEWIS: He has prompted me to actually try and clarify another matter, which is -- it is okay for governments to suggest that say, screening for hepatitis C was not available until September 1991 and that is when they started screening blood obviously. But to suggest that they were not aware about infections until that became available is absolute nonsense. And the same can be said for HIV. I personally was tested for HIV a year before I was informed I was positive without any consultation with myself. More to the point is that once they knew I was positive, surely they were duty-bound to inform me because I was a threat to my wife and family, and I am just one example of many probably, but then even after 1985 when they told me in February of my HIV, there still was no discussion with me about the hepatitis C risk also. Then in 1988 my notes record hepatitis C test.

So if there was not a test until 1989, according to government and not screening of blood until 1991, how the hell was I tested for it in 1988, 1989 and 1990, which were all negative and then I was positive for hepatitis C in 1990. And why I am emphasising this matter? Because recently, a doctor revealed to the observer that they had stored frozen samples from 1979 to the 1990s in their fridges in the hospital in London here and they were going to make them available to the research that was going on with regard to VCJD. I do not think there are many haemophiliacs in the community who have actually been specifically given a date of when they became infected with hepatitis C. They have given me a date of my HIV infection to be some time in 1983, and my consultant attained this information by thawing out samples in 1988 that they had on storage as far back as was being suggested, 1979. This gave them a year by year analysis of negative, negative, negative, positive, which corresponded with my HIV occurring in 1983. But with regard to hepatitis C, when I asked my consultant, he said: unfortunately, the hepatitis C test was not available when we thawed these samples out, so we could not have ascertained when your hepatitis C infection occurred. The big point I am trying it make here, I suppose, is that all haemophiliacs were excluded from the Consumer Protection Act judgment of 2001, Justice

Burton's ruling on safe blood under the Consumer Protection Act. Haemophiliacs were excluded on a rather vague assumption that our hepatitis C infections must have occurred before the implementation of heat treatment of all products in October 1985. Now, that is an assumption they have made and they excluded haemophiliacs from meeting the criteria of that judgment on the premise of an assumption that our hepatitis C infection occurred pre-1985 because we then could not have come into the criteria when the Consumer Protection Act was enacted in May 1988. So I think it is rather irregular and Lord Archer being a QC will understand this -- that surely the law cannot be based on assumptions. Law can only be based on fact and to make an assumption to exclude a patient group from a judgment on an assumption that the infection occurred pre-enactment of the Consumer Protection Act, I find absolutely unacceptable and my own records clearly state that I actually became infected with hepatitis post heat treatment in 1990. I would suggest that these frozen samples in a hospital in London right now, at this very moment, could be thawed out and if all the haemophilia patients could be told definitively when their hepatitis infection occurred -- retrospectively, obviously, but with some definition of when it occurred.

JUDITH WILLETTS: Is that not very difficult because of the incubation period? Would it be hard for them to say -- even though you were tested in 1988, diagnosed in 1990 -- would it be quite difficult for them to pin point when you would have become infected?

HAYDN LEWIS: They would just trace back the tests, and everyone who came back negative would obviously draw a line in the sand, if you want, that anything (inaudible) -- in the negative. As soon as you get a positive test, they can with some certainty say you were infected on that date, or in that year.

JUDITH WILLETTS: What, that the tests were robust at that -- earlier on?

HAYDN LEWIS: There is always going to be some contention about actually how reliable a frozen sample is anyway.

THE CHAIRMAN: I do not think we can do more than enquire about this later. We cannot take it further now.

HAYDN LEWIS: No, it is important that if they had the capabilities to define when hepatitis C infections occurred, that would also emphasise the fact that not all infections occurred before heath treatment started and also that we could have well been and more haemophiliacs, I would suggest, were eligible to actually be included in that judgment. But we were excluded on a strange assumption, one which I have never seen any evidence to substantiate it and my own records contradict it quite conclusively.

LORD TURNBERG: I am a bit confused about the role of the Consumer Protection Act in problems arising from medical treatments because all medical treatments have a risk associated with them. Some patients suffer badly because of the risk. Is that something covered by the Consumer Protection Act? I would not have thought so.

HAYDN LEWIS: Product liability is the premise of the Act as far as the public will expect the safety of British blood. I mean the normal perception -- it was not meant to show any liability, it was just to show that the enactment of the Consumer Protection Act was to to say that we can assume or should assume that everything is attained possibly to make that the safest product possible.

THE CHAIRMAN: I do not think we can make off-the-cuff pronouncements about this. We will have to go back and look at it.

HAYDN LEWIS: It is just that he asked to clarify that.

ANDREW MARCH: I just wanted to clarify that we have recently seen minutes that detail that NIBS -- that is the National Institute of Biological Standards and Control -- are soon to make available sequential sera from UK haemophiliacs from the 70s to the 90s and the reason that this is so valuable to research is because it shows that delineated stages, where variant CJD -- different strains of disease and incubation -- so these samples are incredibly valuable because there is not really any other group who are implicated for having been exposed to variant CJD that would have so many different samples of sera on record frozen, so they are technically valuable and I can quite see why the US food and drug administration are seeking to get hold of those.

THE CHAIRMAN: Yes.

HAYDN LEWIS: That actually adds to a recent submission that the panel received from, I think it is GRO-A, looking at a case where he was given blood that was clear, when it was donated with HIV, and then consequently two months later the donor tested positively. But blood cannot be heat treated. So obviously there is this little window of opportunity where the donor then can be called back and then obviously they would not take another pint of blood off him. With regard to these stored samples and the nvCJD test, because they have done a year by year analysis to test, they can with some certainty suggest how long a false negative would be a threat, if you want, because the test would be more specific to at what at a stage the incubation was at and earlier obviously the more confident they can be that that pint of blood donated is clear of that infection, so this sort of timescale of samples is crucial.

LORD TURNBERG: It is obviously very important research to be done, very essential that we have it.

I understood -- I may be quite wrong -- this the prion that causes CJD and variant CJD is carried in the cells rather than in the plasmaral sera but you are suggesting that they have a serological test, test of serum, because they do not have the cells in there, the white cells in particular which they deplete from blood transfusions now. They remove those now in blood transfusion. I wonder whether they have a serological test or whether that is something that they want to find out about.

ANDREW MARCH: The prion that they are looking at is described as PRPSC which I believe is related to the Scrapie, which is more sensitive. The veterinarian tests are sensitive enough to pick this up and some of the technology is based on that and they have transferred it and used that sensitivity but we have definitely read about sequential sera and somehow this is useful -- it has been discussed in this context.

LORD TURNBERG: We are very interested to see how they do, very important.

THE CHAIRMAN: You say you have read about it. Do you have the texts?

ANDREW MARCH: Not with me, no.

THE CHAIRMAN: As a reference?

ANDREW MARCH: Yes.

HAYDN LEWIS: It will show that this is a good test and so far the only way of defining it is the autopsy stage and a sample of the brain and so forth. Unless the diagnostic readings suggest that there is a criteria, then if you succumb to certain elements that you would be identified as a possible case, but it is not confirmed at the moment, until you die. But what I find unacceptable is that okay, the test might not be cheap enough or robust enough at the moment to implement into the screening of donated blood but also right at the very moment the Department of Health have asked for the consultation as to the risk factors of any one pint of blood having this infection, because obviously it will be, in the department's eyes, uneconomical to screen British blood if the chances of it being infected were so low that it was not cost effective to screen blood for VCJD. An example, recently in Birmingham someone succumbed to HDRV1, and the Department conceded liability, because they had not implemented a screening procedure for HDRV1 because the risk factors were so low. It was uneconomical to screen every pint of blood to avoid that happening, so they allowed it to happen and paid the consequences to the tune of, I think, £750,000 to the unfortunate -- only one victim to date. But they have already screened over 10,000 donations of British blood in America anonymously gained from donations of blood to the national pool, if you want, and they have found three positive cases in 10,000, which is encouraging. I do not want I do not know what that works out statistically in a national population but it is encouraging out of 10,000 American donors there were almost no positive tests at all. So the BSE group, if you want, is a pretty low one.

THE CHAIRMAN: The question really is at what point does the cost risk -- affect risk factor merge into Russian roulette.

HAYDN LEWIS: But the same surely cannot be said for the known at risk and identifiable patient group. It is okay them having deliberations about risk factors with regard to screening blood for the national population but the same cannot be said with regard to a known and actually known group who they know have received an implicated batch.

THE CHAIRMAN: I think we have that on board.

HAYDN LEWIS: The same was done with hepatitis C, you see.
There was a test available, but they put my family at risk by not immediately telling me in 1988 that I had actually had a test for it.

THE CHAIRMAN: I think we have grasped that.

HAYDN LEWIS: I can lose the plot as far as the Machiavellian approach that currently at that time in 1988 that writs had been issued against the Department Of Health with regard to my HIV infection and they certainly were not going to then inform all plaintiffs that they actually had hepatitis C, but I found it pretty disgraceful in 1991 to ask them to sign a waiver to disregard any future responsibility when at the same time they actually knew that I was infected with it.
That really needs to be looked at in great detail but unfortunately the Department of Health do not particularly wish to discuss it with me. Maybe they will talk to you.

THE CHAIRMAN: It needs to be looked at, I agree.

HAYDN LEWIS: Thank you.

LORD TURNBERG: Perhaps one comment on the pharmaceutical companies and this business of named patient. I am not in the business of trying to defend the pharmaceutical companies but by and large the named patient use of drugs is of very little use to them in clinical trial terms. They do not find it very useful, so they are not in business of trying to sell it on the basis or give it for named patients. Their motives are certainly not in favour of the named patient. It is usually the doctors who think that there has been some marvellous advance like the Herceptin case for breast cancer, the doctors were really pushing it. It was a new treatment, it sounded as if it was fantastic and that is what is happening with this drug at the time, they pushed for it rather than -- I think the pharmaceutical industry may be at fault with all sorts of they think but that particular one is not arguable.

HAYDN LEWIS: Whatever the product is used for, surely if they say it is for a named patient, then the patient should be told about it and consulted. That never took place in many cases, I would suggest.

ANDREW MARCH: I would like to quote something from the minutes of the committee of the safety of medicines on 13th July 1983, where they expressed concern about the named patient basis:

"The subcommittee learned that manufacturers were producing advertising material for the use in the UK which appeared to make unjustified claims concerning the safety of heat treated Factor VIII. It is advised that this should be stopped. It is feared that unlicensed material could be used on a named patient basis despite the fact that safety and effectiveness had not been established or considered by the licensing authority."

THE CHAIRMAN: Where do we find that?

JUDITH WILLETTS: Page 8.

ANDREW MARCH: I would like to draw your attention to the word "manufacturers" where the initiative here does seem to be coming from the pharmaceuticals.

THE CHAIRMAN: Thank you very much.

VIJAY MEHAN: Can I ask a very simple question. A simple question, it may be a difficult answer for you. What do you think would bring about closure; is it trust, truth, an apology, or financial recompense?

HAYDN LEWIS: What would bring about closure. I think a little bit of humility shown by the people responsible would be a big start as far as bringing some closure because to date I feel we have been treated with utter contempt and that surely is not acceptable in today's society. If you ask me as far as monetary matters, it is never going to bring closures but it certainly would bring some contentment to all the widows, for instance, who would feel that maybe their partners did not die in vain and there was maybe some recognition for that unfortunate event. As far as closure, I do not think any of the haemophilia community are on some lynch crusade, if you want; that we want to name and shame or bring people to account. That is not our intention.

I think it is difficult -- and I refer to the MacFarlane Trust, if you like, but they have hit a rock and a hard place. They are trying to address the needs of their registrants from a moral perspective because that is all that has ever been conceded by government at the moment, but how do you in all sincerity address the need of registrants from a a moral perspective when the very registrants know full well the fact is that the government have a legal responsibility to us, even though it has never been judged that court of law. I will challenge anybody to defend that if you used crown immunity you accepted liability. All it was was a way of exonerating the NHS which, as it stands I do not actually perceive the NHS as at fault here. If you go back to the self-sufficiency issue and the targets that were asked for, the Department of Health were clearly told in 1974 that the national targets to achieve self-sufficiency were 40 million units. So why do I read in the minutes of 1978 that the Department -- and it actually was referred to in the self-sufficiency report -- that self-sufficiency targets had been attained in 1977 because the maximum capacity at Elstree had been reached, which was only 14 million. So that suggests that the department were heading for that target of 14 million, whereas the medical profession were expecting a target to be achieved by 1977 of 40 million. When you think of the doctors' mindset when he first started to bring those products into the country in 1974, he was doing it on the premise that the patients needed it, but he was also doing it with some assurance and some confidence that the government had stated that he would only have to be doing it for three years because then British voluntary work would overtake, but unfortunately in 1976 the government had eventually got to the stage where they had number crunched the costs involved in attaining 40 million units of national population of blood, which would meant 80 per cent of donated blood. It also would have meant investing 20 million plus pounds to facilitate that process, and they immediately I would suggest switched off from any policy of self-sufficiency in 1976 and we are all aware, then, of the consequences. But that also explains register Lord Owen's money was not used into the facility to produce Factor VIII. They had a capacity capable in 1974 of 14 million units of Factor VIII. All they needed to do to obtain that capacity was actually encourage more plasma into the process. So they never had any goal of attaining

40 million in 1975. Their goal was attaining maximum capacity at Elstree, but unfortunately nobody discussed this with the medical profession at the time and they were always going along this road of understanding that by 1977, 1978 at the latest we would have been self-sufficient. Could I just make one final point about this: research is obviously necessary in any field of medicine or technology or anything, and there is an easy way and a hard way of achieving it, and sometimes, if you look at it along the lines that everything they had done, if you can either question the patients were not consulted with, doctors were not really forth coming about the risks and so forth but if they had attained all that research using only British donated blood they would have come up with the same answers as they did from using the American stuff, but they would have had a greatly reduced infection rate. And that is the shame in all this, that the British government, if you want, could not see the urgency, if you want, of actually putting some money into what it was at the time, a patient treatment issue, but actually they should have been thinking and more importantly from 1975 in Lisbon, they had already been trying to work out what was the future risks from hepatitis. But unfortunately they do not look further than the end of their nose, the British

government. We are all sitting here today discussing the consequences obviously, but going back to the question of closure, there is a perfect model within swimming distance, in southern Ireland. The emphasis of that scheme was not to look at where the infection came from. It does not matter who produced it. It does not matter who the donor was. What matters is, that citizen is infected and the Southern Ireland scheme sort of -- the Irish common sense if you want is let us concentrate on trying to help the person infected and we can sort out whether he was infected from a British product or a measure products or whatever country he came from. That is not the important issue, the issue is that they are a citizen of Southern Ireland and they deserve our attention to their infection because they are innocent in the way that they actually attained it.

THE CHAIRMAN: I think we have grasped that.

HAYDN LEWIS: Good.

LORD TURNBERG: That was a very helpful comment at the end. On a factual basis, do you have any numbers of patients who were given blood products on a name patient basis or on a private source, do you have figures for that?

HAYDN LEWIS: There are not any because there are no records of it. An example: There is no record in my importantly records of -- well, for instance, right, a day a consultant calls me into their office and says unfortunately, Mr Lewis, I am afraid you have HIV. How do you feel about this? I said what are the consequences of that. He said at the moment I would suggest that it will not even progress to aids because predominantly you have not received different infections as you would say the gay community, for instance, but you would have expected some kind of record in my notes, a consultation of that nature, you would think the doctor would make a note of it. There were no notes made of that consultation. There were no notes made of when I was told of my hepatitis C. There were no notes made of when my wife was told that she was also infected.

LORD TURNBERG: There might be some record of the prescriptions, though?

HAYDN LEWIS: From a pharmaceutical departments? In fact that is where you will find any consent forms or any --

THE CHAIRMAN: Do you have your records?

HAYDN LEWIS: Not on me, no!

THE CHAIRMAN: I do not mean on you! Do you have them in your possession?

HAYDN LEWIS: They are rather large, they will fill a Sainsbury's shopping trolley, that is for sure! I have looked through every page. There is no consent form in my records.

LORD TURNBERG: I was not asking about consent, I was asking about the -- (Overtalking)

HAYDN LEWIS: I am not aware of any numbers at all.

LORD TURNBERG: I think you might be able to get that.

HAYDN LEWIS: I would love to see them. I would suggest you are not going to find any.

THE CHAIRMAN: That has been a fascinating session, whatever else. Thank you very much, Mr Lewis, Mr March, I am most grateful. Thank you. I think our next evidence session is on 14th June?

(3.03 pm)

(The inquiry adjourned)