Hearing on 11th July 2007
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Wednesday, 11th July 2007

(9.30 am)

(Proceedings delayed)

(9.47 am)

THE CHAIRMAN: Good morning. First, our apologies for the change of venue at short notice. It transpired that our usual venue had been double booked in error, and this was made known only late yesterday afternoon.

I am very grateful to our colleague Lord Morris, who was here when I was not and stepped into the breach and rescued us, and Vijay's prompt actions together with his at least made this possible.

Our apologies to those who are outside, because you may find it difficult to hear, but I am not quite sure what we can do about that.

Secondly, I have an unhappy announcement. Lord Turnberg will not be able to continue as a member of the panel owing to a very sad family tragedy. We have, of course, sent him our thanks for the valuable contribution he has made so far and the generous time he has contributed, and of course we have told him of our sympathies. But we have been fortunate to be joined by Dr Norman Jones, who, like Lord Turnberg, is a former treasurer of the Royal College of Physicians. A treasurer in many of the London colleges, as you

probably know, is the equivalent of a president. He is a close friend of Lord Turnberg, and he readily and generously agreed to step into the breach.

I fear he will have a formidable task because he will have to bring himself up to date by reading the transcripts of all the evidence which has been given so far, and all the documents with which we have been supplied, so that it may take him a little time to read himself in. But we are very grateful to him.

I would like to ask Lord Morris to say a word or two about Lord Turnberg, because it was he originally who invited him to join us and received such a ready response.

Address by LORD MORRIS

LORD MORRIS: Lord Archer, I rise to join you in deep sorrow. None of us here has words even remotely worthy of addressing the scale of the tragedy which so sadly and so cruelly has befallen our good friend and Parliamentary colleague Lord Turnberg and his wife, Lady Edna Turnberg. We can only hope and pray that he and his wife will have been comforted to know that so many others share their grief. They are very much in our thoughts.

It was Leslie's humanity and abiding social concern that prompted his involvement in the Inquiry, and it was

that same humanity and concern for others, in his case for people among the poorest and politically least influential on earth, that led to his son's so utterly untimely passing. And all of us honour his memory and draw inspiration from the nobility of his example.

THE CHAIRMAN: Thank you very much. One of the first things that he said to me after the tragedy was that he had now shared the experience of so many of the people whose experiences we have been hearing about.

THE RT. HON LORD OWEN (called)

THE CHAIRMAN: We are very grateful to Lord Owen for agreeing to come here today and give evidence. Lord Owen, would you like to begin by summarising your evidence and then perhaps we can ask some specific questions afterwards?

A Well, as you say, Lord Archer, I have submitted some written evidence, two pages, a summary and a suggested chronology, because I notice the chronologies that have been published by the department have very significantly omitted a large part of the information that has been given to Parliament.

One of my main concerns is that Parliament was told that we aimed to have a target date of self-sufficiency in blood products in two to three years -- that was in 1975, so it was 1977 and 1978, and I hope the Inquiry

will find out when Parliament was properly told about why there was a delay, was this a decision taken by ministers, or was it a decision taken by civil servants, and in my view, if it was, why was the Ombudsman so unwilling to investigate on a maladministration case which I presented to him way back in the 1980s.

The other issue which I hope you will also be able to elicit is why my own private papers were pulped. I mean I would be staggered to wake up suddenly and find that my private papers as foreign secretary had been pulped without my consent, but I admit there is a difference in that I was only Minister of State, but the issues we were dealing with were extremely important, and to suddenly find that, under an alleged ten year rule, ministerial papers can be pulped, and we are not allowed to disclose these documents for 30 years, seems to me to be rather bizarre. But much more important was the pulping and destruction of departmental papers from February 1989 to 1982.

Now I kept on mentioning to journalists and others they should look at France. I must say I have not done this before, but I think it is very important to just state facts, and whether they will lead us a to explanation of the pulping and destruction of the departmental papers I do not know. But by 1989 it was

very well known that there was a major scandal underway in France, very similar to the circumstances here.

Indeed it was so made very public when a group calling themselves Honour of France blew up a car of Dr Michael Baretta(?) of Paris-based CNT. He was then, with others, found guilty -- three out of four defendants found guilty, including Dr Baretta, who received a four-year prison sentence in a trial in June 1992. So in the very period from May 1989 between February 1992, when it is now admitted at long last by the Department that there has been a destruction of documents in the Department of Health, and almost a total filleting out of all the papers relating to the inventory, that did coincide with it being a world scandal and well-known in this country, but there are those who -- and I think this is a very important -- I am not capable of making that judgment.

Then I must say it is an extraordinary situation that there is just this one little piece of paper which relates to my period in office which came up in the documents, although I will say it is an extremely interesting piece of paper and it is mentioned in the Guardian today, but what it reveals is it reinforces my memory of the whole events, that there was resistance in the department to going for self-sufficiency. I cannot

remember exactly why, I suspect it was the deep financial pressures we were coming under for the Health Service budget. Also a tradition of thinking that the Regional Blood Transfusion Service was to a great extent autonomous, and they did not want the department officials did not want to tell them how to spend their allocation of money and how to choose their priorities.

Nevertheless this document does make it absolutely clear that, "The department" -- and I quote, this is 20th February 1976:

"The department has sought to have this project given special priority, and it seems to me [this is the unknown person who wrote this] that we must now devise some means of ensuring that Oxford are able to let the contracts and get on with the necessary works."

And Oxford is a reference to the very big facility in the Regional Blood Transfusion Service at Oxford.

In the first paragraph it also summarises really quite succinctly what they knew:

"Quite apart from this the alternative of buying the commercial product (with its higher Hepatitis risk) is more costly than producing our own."

And it ends by saying:

"I should be grateful if you could consider as a matter of urgency what can be done. The Minister of

State [which was me] has called for another progress report on AHG production, which we must let him have in the very near future."

So this sole document really covers most of the ground about what we knew at the time, and previously I have not been able to enforce this, because I am just relying on my memory. Anyway those are the main points I wish to make, and I think it is more important to use the time to answer any questions that you may have.

THE CHAIRMAN: Thank you, we are most grateful for that. Just taking up the point about the Ombudsman, as I understand it, the principal reason the Ombudsman gave was the rather significant one that it was not maladministration, it was the consequence of a political decision. Is that what you understood it to say?

A It was a very extraordinary letter, the one that was sent to me by the then Ombudsman Mr Barraclough. He actually questioned the basis for my decision. He argued that because I had not said in my answers to the House of Commons that I was afraid that the blood was contaminated, I was making this decision purely and simply on cost grounds. I then entered into a conversation with him saying, "Well, how could I, knowing that haemophiliacs were" -- there was no alternative, we had decided to import blood products a

year before I became minister, we had no alternative.

Now, I mean it is always a very different question for ministers to reveal a risk or to get on as far as possible to reduce the risk. I took a choice to reduce the risk, and it seemed to me the right choice at that time.

He then went on to make -- discussions about the question of the medical aspect, which I felt could only have come from him having access to medical information. So when I asked the Ombudsman most recently, this year, to look back through their records, which again you will see from the letter from the Ombudsman they don't keep any papers, they don't have any records, they don't even keep hard files, computer files. And I find the whole structure quite extraordinary. It appears -- I am not yet understanding -- does the Ombudsman go back to the ministry of health for their medical information but at that time of course I was not able to say to the Ombudsman look here there is a memo here which makes it quite clear we knew there was contamination but it has become very obvious that the medical profession were well aware of the risks of contamination in 1973 and on progressively as the years went by.

I did complain to the Select Committee on the Ombudsman. I do not know whether you will consider this

in your terms of reference, but instinctively I am against people suing the Department of Health. I am sure you find this yourself, I have often discouraged constituents and it has to be said that the many of the Haemophiliac Society and others only went to the court of law when there was no alternative; they were right up against the deadline when they had to have a group decision.

I have always personally been attached to a no fault compensation scheme, and that underlies my feeling. I always understood the creation of the Ombudsman was to try and get satisfaction without having to go to court. I had to -- they would only look at an individual case. Fortunately, I was able to have in my constituency a person who at that stage was a haemophiliac and had tragically developed AIDS. He gave me permission to use his case. I found every possibly obstacle put up by the Ombudsman, and successive Ombudsmen, and incredible delays. All I can say is, if that is the structure that Parliament is relying on to try to avoid people having to go to court -- and most people don't want to take doctors to court, they know mistakes can be made, they just want to know the facts -- I think we need to look at the whole question of Ombudsmen.

THE CHAIRMAN: Well, some of us, of course, argued very

vigorously as long ago as the 1960s and 1970s for a system of no fault liability for all kinds of reasons.

A I think you and I were at ministerial meetings that argued the same and we were on the same side.

THE CHAIRMAN: Indeed. But when I said that the Ombudsman gave us a reason that it was a political decision, I did not think -- I may be wrong -- that he was referring to your ministerial decision; I thought he was saying, "You are complaining about events which happened after you left office. The reason why your intentions were not fulfilled was because of political decisions and not maladministration". Whether that was right or not, that was what I understood him to be saying.

A Yes. I think that was, but he had not produced any evidence for that.

THE CHAIRMAN: Well, no.

A I come back to the other question which is, it was a very narrow definition of maladministration. I mean, as we all know, ministers make decisions and they let Parliament know. In this case it was an important decision. We were allocating in those days only half a million pounds, but half a million pounds was quite a lot in those days, with the pressures and constraints. I did it in written answers, so it was a conscious decision; I wanted Parliament to know.

The understanding is that if ministers, or if the Department is unable to meet a public commitment that is made to Parliament, there is an obligation on the officials to notify ministers and then for ministers to come to Parliament and say that we have not been able meet that date, explain why -- and in many of the cases there is a perfectly rational explanation -- but the fact that they did not know and that people were believing that there was going to be self-sufficiency is a very material fact, because the haemophiliacs were well aware of the worry that was around blood supplies and they were given to understand that we would be self-sufficient by 1977 or 1978.

Now, I do not always think that you can expect ministers -- some minister comes in and inherits my decisions, governments changed during this period, and I think the onus is on the civil service to come to ministers and say, parliament needs to be told that we have not fulfilled the obligation that has been said to them.

THE CHAIRMAN: Yes. I wonder whether we could just now fill in the parameters in terms of dates just so we know where we are. I think you were appointed to the Department in March 1974?

A Yes.

THE CHAIRMAN: Initially as Parliamentary Secretary?
A Yes.
THE CHAIRMAN: And then a little later that summer as Minister of State?
A Yes.
THE CHAIRMAN: And I think you moved to the Foreign Commonwealth Office in September 1976?
A Yes.
THE CHAIRMAN: Could I ask you this. What first drew your attention to the problem of infected blood products?
A I read a very remarkable book by Richard Titmuss called The Gift Relationship. I cannot remember exactly, but I know I read it before I became minister, so it was probably 1972. I think it is a very remarkable book, and very rarely do sociological studies have such concrete evidence underpinning their theories, and for those who don't understand it, it is worth remembering. It was a belief that a blood transfusion service that was based on what he called loosely "the gift relationship", where people were not paid, where they came in as volunteers, who were given a cup of tea and that was all, were much more likely --
THE CHAIRMAN: I can remember this, because I gave blood at that period.
A Well, they were much more likely to answer correctly

where they had a probing question such as, "Have you ever been yellow, or have you ever had jaundice?", than somebody who comes in and is receiving payment for their blood.

Now I remember this vividly, because when I read the book I remembered when I was a medical student in Greece and was short of money I had given blood and been paid for it. So it was a vivid thing. I knew the cash relationship would change the likelihood of you being completely straightforward about this. Then we knew from what Titmuss was describing and what was already well-established -- he was working on well-known facts -- that a lot of the blood donors were coming from communities that were into drugs and therefore were always potentially at risk to infections. Of course in those days we had just come to know about Hepatitis C, but we still did not know about HIV.

THE CHAIRMAN: And if I remember, at that period the serious nature of Hepatitis C had not become clear, had it?

A The possibility of getting cancer as a result of having had jaundice from Hepatitis C was not very well-known, no.

THE CHAIRMAN: Could I just ask you this --

A Cancer of the liver.

THE CHAIRMAN: Yes. Within the Department was this

something which was well-known that there were problems with blood purchased abroad? Was it a general topic of conversation, or was it something which only reached the surface very occasionally when it appeared on a minister's desk?

A I cannot remember whether we discussed it collectively with ministers. We used to meet once a week. Barbara Castle was Secretary of State for Health and Social Services, and she had then two ministers of state: Mr Brian O'Malley was the social security and I was Health. Then we had the Minister for Disablement, Alf Morris, and Sir Jack Ashley was Parliamentary Private Secretary for Barbara Castle and we would discuss every week what was happening. It may well have been raised in those sorts of issues, I cannot remember.

But I mean, as for making public statements, making speeches about them, which are enclosed in my evidence, again the Department in their chronology really downgrade the fact of how frequently Parliament was informed about this. There was a World in Action programme on this in 1975, a transcript of which I have given, and they then went on to do two other programmes and, as I say, there was a press release, which they say was put out by the Department, but it was a speech which I had made in a big international conference.

THE CHAIRMAN: Yes.
A It was well-known and the haemophiliac world, who was watching these things very closely, were well aware of what was happening and many of them knew, really, the background to why we were doing this. It was not just on cost grounds.
THE CHAIRMAN: You said a few moments ago that there was a certain reluctance in the Department to do much about self-sufficiency. If you do not remember this please say so, but we have rather formed the impression that there was a debate going on -- quite a well-informed debate -- and the argument for self-sufficiency was first that imported products were suspect and, secondly, as you say, some people seemed to have been impressed by the additional expense of imported products over home produced products.

But on the other hand, there were those who were saying if we ceased to import products this would reduce clinical choice and, secondly, that it is dangerous to tie yourself to one source of supply, because if anything interrupts that you would not have any source of supply at all. Do you remember this debate?
A I think I do remember it. It was very -- you know, we are talking a long time ago.
THE CHAIRMAN: Indeed.

A But I do remember this debate and I think my answer to that would be -- well, firstly, I was not in the position to instantly announce self-sufficiency. We had to get the capital programme, we had to increase the number of blood transfusions, we had to make a whole lot of decisions inside the Blood Transfusion Service, so I knew it would take time. Furthermore, I knew that there was great dangers in just allowing this money to go into the regional health allocation and that is why there is talk about there being special arrangements, and we made at this time also special arrangements for that class of patients who needed to go into treatment for their violent behaviour, but whom we did not want to put in prison and we did not want to put in Broadmoor and other hospitals. So there had been a report by a previous home secretary, Rab Butler, about this, and he earmarked money for the regional health authorities and told them to spend it on this; it was earmarked money.

Three or four years later, through various investigations, Parliament discovered the regional health authorities had taken this earmarked money and not used it. Now, that is a classic case of why it was difficult: this idea of autonomy of decision-making was quite strong. I think that was beginning to come up in this Oxford reluctance, but that is why I had a series

of minutes, or deadlines, in which they had to report to me. I was worried that they were not going to fulfil it.

Anyhow, these sorts of debates are very attractive aspects of the openness in the Department of Health. I mean the Department of Health is a pleasure to be in. By and large the civil servants are very committed to the Health Service and want to make it work, they are living with constrained resources and they are having to make all the time decisions as to where you were going to spend money -- if you like, rationing.

But my experience is, once the minister made up his mind -- in this case I decided we were to go for self-sufficiency -- then they carried it out. So I do not believe it would be in the Department, the lack of -- it was probably in the regional transfusion service where there was a sluggishness and slowness and that should have been monitored very carefully, and from all the evidence in this memo it was being monitored. So I think the Department officials were well aware by 1977 and 1978 that we were at a low target now. It is also very true that more and more people were using blood products, more and more haemophiliacs were using blood products.

On a question of whether there should be a choice, I

think there should be a choice of treatments, but I do not think there should be a choice of treatments when there is a very high risk of further contamination. So I think it would have been perfectly legitimate, once you had got self-sufficient levels and were reasonably confident you could meet all the demands, to withdraw products from abroad. That was certainly not a decision I was capable, or would have wanted to take in 1974, 1975 or 1976.

THE CHAIRMAN: And of course when you say "choice", presumably it would normally be the choice of the patient after a patient had had the situation explained and what were the arguments?

A Yes. I mean haemophilia is dealt with by a fairly small group of doctors who specialise in it and become very expert in it. The general practitioner helps, of course, in that sort of thing, but the number of doctors who are specialists in the country on haemophilia -- I do not know how many there are, but they are not a very large number. They are a closed community. They know about all this debate and they are linked in to the Blood Transfusion Service and they know about what is happening. These are dedicated people, they see these patients in regular time and they often see them getting worse, so they are extremely keen to control the

bleeding and the side effects, therefore, of the bleeding. I think they want the best for their patients.

There was never any question of we were not going to provide this because it was not cost effective. We were a long way -- I used the word "rationing" in 1975 about healthcare and that was considered a very bold and rather dangerous thing to talk about, but of course it had been going on for year years and it is much more overt now and we have a formal structure.

THE CHAIRMAN: Exactly. Now, I wonder whether you can help us with, perhaps, the ethos of that period. We have had a lot of evidence from people who themselves or their families were given infected blood and one of their complaints is: we can see what the dilemma was, but it was never explained to us and we were not given the choice.

Now, would it be fair to say that at that period doctors tended to be less informative to their patients than they are now?

A Yes, I think there is no doubt. There has been a sea-change in what we consider the rights of the patient and I think now this would be considered almost by every doctor that the right of the patient would be to explain to them the risk of these things and they would be done.

There are some people who regret the change, and I suppose -- but I am no longer a doctor in a proper clinical sense, I am not -- even my family do not think I am safe to treat them now, and soon the GMC will stop me treating myself, which I object to very strongly. But I think that is a change which has taken place -- freedom of information, the whole culture has changed -- and I think most people would say, and my friends who are doctors tell me, that on balance this has been an improvement.

But there are sometimes downsides. You have to confront people with risks which they are not always capable of understanding and cause a lot of fear -- and some would argue, from the old system, unnecessary fear. But I think that we were a hierarchical profession and probably still are.

Anyhow, these are discussions that are being debated very fully in Parliament and Parliament has made its choice in most cases and personally I think it is correct. So if I was now a doctor and I could move myself back to 1976, I think I would have a much bigger debate amongst myself as to whether this should have been told to haemophiliac patients.

THE CHAIRMAN: Yes, thank you. Could we look now at the reasons why your intentions were not fulfilled as we

have them partly from the Department. First of all, I think as you said, there was a greater demand for these products than the expert committee had originally envisaged, was there not?

A There is no doubt that that is the case. I think there is a rather informative letter which I wrote to an MP about this whole question and I revealed then really almost all the facts. I think it is in 1975, a letter came to my attention from my own personal papers and I think that gives about as good a description of what we were feeling at the time.

THE CHAIRMAN: I think we have it. I think we will probably have to index the documents we have now much more closely than we have in the past.

A I think I make mention of it in the ... It is correspondence between myself and the then Labour MP Andrew Bennett MP, on 4th December 1975 and 23rd February 1976. It is attachment two in my submission to you.

THE CHAIRMAN: Yes.

A I thought that was a rather detailed description.

THE CHAIRMAN: Indeed, yes. So you accept what we have generally been told: that there was this escalation?

A Oh yes, I have no doubt whatever and I think that my successors would have been faced with the question of

having to find more resources and to increase the number of blood transfusions.

THE CHAIRMAN: Yes.

A If we were going to keep pace on the target date which I was setting. I would have thought that was maybe even becoming apparent in 1976, but it is pretty clear I must have held a meeting soon after that note of 25th February and then I made another statement to Parliament and I would not have made that unless -- I mean on 28th April 1976 in a written answer, at column 106:

"Provided that sufficient donors remain willing to give blood, the National Blood Transfusion Service can generally satisfy the demands made on it."

There was always this worry that we were not going to get quite enough donations and that was one of the problems.

THE CHAIRMAN: Yes. Well, the other reason which seems to have been given is that although provision was made to increase the volume of donations, no provision was made for processing the products once they had been collected. Can you help us at all on that?

A Well, that was one of the things that was done by the Oxford facility, from what I remember, and they had to increase their production. I cannot remember the exact details. Then much later on in early 1980s came the

question of building a new facility and there was a delay over the building of the facility and I am not quite sure what underpinned that.

I want to be quite clear. I do not believe that there was a conspiracy. I mean people were not deliberately trying not to meet these targets. What I think was wrong was the Department was not told more about this dilemma during this period, but I have not really done any research through the Parliamentary answers in the period in which I was no longer in the Department, so from 1976 right through to 1981/1982 I do not know the extent of the questioning. The questioning comes very strongly again in 1987 and 1988, but I do not know what the questioning -- how much was revealed to Parliament at that time.

THE CHAIRMAN: I think your evidence is the first occasion certainly that I had grasped that it was not only at the Blood Products Laboratory Elstree which was processing these products, but there was also one at Oxford?

A Well I think so. I cannot remember it exactly. You see it says here:

"If we are to continue to insist that any extra capital required must be met out of next year's normal allocation, it is understandable that Oxford would wish to assess the priority of AHG production against all the

other commitments which the Regional Health Authority have to find money and the authority's order of priorities may not be the same as those in the Department."

Then it goes on to say:

"The Department have sought to have this project given special priority and it seems to me that we must now device some means of ensuring that Oxford are able to let the contract and get on with the necessary works."

So we are talking more than just blood transfusions. We are talking about works which needed a capital sum, and I think at that stage most of it was going to Oxford. We were also getting some blood from Scotland, where there has traditionally been more production than they needed and there was cross-border allocations.

THE CHAIRMAN: Yes, we saw that. We were also told that in I think July 1979, which of course was after you left the Department, there was an inspection of the facilities at Elstree, which produced a rather disturbing report about hygiene and so forth?

A I think that is true. I only became aware of that in the late 1980s, but I think there was no doubt that there was some problem at Elstree and it had not had enough capital allocation. There was a very interesting

article on the Blood Transfusion Service and the National Health Service in the British Medical Journal on 12th September 1987, which I have included in my evidence to you.

THE CHAIRMAN: Yes.

A Then there was some lively correspondence in the BMJ from those defending the Blood Transfusion Service and those who were critical of it. So I think that gives you a pretty good cover of the different opinions about the management of the Blood Transfusion Service in the 1970s and early 1980s.

THE CHAIRMAN: This may be difficult, because it was a long time ago, but can you recollect when you were in office whether your attention was ever called to problems at Elstree?

A No, I can't. To be honest, I just do not know. I am fairly sure there was a -- in the controversy over finding out how much money we needed to find and how to get self-sufficiency, there must have been some assessment made about Elstree, but I cannot remember it. The normal thing would be to go back to your papers and find all the minutes of the meetings and know who was there and who was responsible. I do not quite understand, for example, why all the names of the key people on this document are blocked out.

THE CHAIRMAN: I quite agree. One of the problems that we have had is to discover who was writing to whom, but that is obviously something we will have to address in the future.

I think those are the matters which are uppermost in my mind. Judith?

MS WILLETS: I just wondered to what extent you were aware of, or where the knowledge would have been in terms of when purchasing products from abroad what the protocols and processes would have been in terms of granting licences for those products to the purchased. I wondered what the background was?

A I very much doubt that I went into that detail. I think perhaps when the first decision was taken in 1973 to go and buy blood products abroad, whoever made that decision might well have gone into the background of it, but I do not remember doing so.

I mean, I want you to get clear, I do not think there was any argument among the doctors about the risk of contamination. I mean, this thing makes it clear. They are sensible people, these people. By and large, the doctors in the Ministry of Health are people who specialise in public health and they are people, therefore, who are very much more aware of this type of problem; they are not so much clinicians, they are

people who, by and large, are experts in public health.

The problem was treasury issues. Were we entitled to tell the regional health authority that we would make it self-sufficiency? Well, I decided we were. Were we able to make some special earmarking of money? Well, in this case it appears there was an open debate between Oxford and the Department and they knew that we wanted it, so I do not know.

MS WILLETS: The original half million; there were subsequent quarter of a millions scheduled to come in in the subsequent years, is that right?

A Well, there would certainly have had to be, once you started having much increased demand, so you would have needed more facilities. So it is perfectly reasonable for the next government to have done something about Elstree and started to build another plant there, perhaps. That would have been a necessity and that was a much bigger expenditure.

At that time presumably once again the question of self-sufficiency and the arguments were entered into and presumably were sustained. But, I mean, I do not quite understand why we are not told which civil servants made this decision to scrap all these documents. I mean, we have a history of the National Health Service, the historian -- the point about the government -- has just

gone through and written a wonderful history of the National Health Service. Who decides what documents he should see? How can you write a history of the National Health Service when people can destroy the whole segment of documents? This was not just a few documents, this was selectively going at the subject.

Well, I am very against conspiracy theories, because they are usually torn out to be failures. The foul-up theory is much more frequent. But the more you look at this, the more you look at the question of what was happening in France, the more you begin to see people who were fearful of having the same legal processes going on in London and in this country, I think at the very least the government, having at long last announced -- after all, they are not responsible, this is years ago. But they did eventually, under pressure from Lord Morris and others in the House of Lords, they did have this investigation and they now tell us this took place, they tell us it was an official who did this on his own, and I think we should know who this official is and we should actually hear from him and, if he is still alive, ask him to give evidence.

THE CHAIRMAN: I think we will be asking some questions about that.

A I am very pleased to hear it, thank you.

THE CHAIRMAN: One other matter that I did intend to ask you about. A product cannot be imported and used in this country, can it, until it is licensed under the Medicines Act?

A Right.

THE CHAIRMAN: Now, as I read the Medicines Act -- and this is a lawyer not a doctor talking -- the Secretary of State is responsible to be the licensing authority. Fairly clearly he can't do that himself --

A Or she.

THE CHAIRMAN: Or she. They are advised by a committee. I wonder whether you could tell us any more about that process and was it something that was frequently brought to your attention?

A The Medicines Act under which that operated on was a very interesting example, a very early one, of government and industry co-operating very fully and in my view it was a very successful legislation. It allowed us to attract many pharmaceutical companies to invest in research in this country and they had confidence that there was a transparent and open system of assessment in which they participated as the industry. So it was jointly done between civil servants, government scientists and people from the industry. There was a great deal of confidence in the

Medicines Act at that stage.

I was actually the sponsoring minister for the pharmaceutical industry in those days -- it was later taken away -- and it was a very good relationship, in fact so good that I argued inside the government, and got permission for one moment, to use the Medicines Act to deal with smoking, but it was eventually dropped. But I would defend the Medicines Act and its procedures. It is certainly one I had a lot of confidence in, but it was definitely joint, in which industry felt they had a full say.

THE CHAIRMAN: I see. But the final say was with the committee presumably?

A Yes, the Secretary of State would be advised by the committee. The politicians would not get involved in that. I mean, by and large, we have to take advice and in an area like medicine you are really heavily dependant on the scientific and medical advice which you get. Occasionally I would challenge it on the basis of inadequate medical knowledge, but ...

THE CHAIRMAN: Thank you. Vijay?

MR MEHAN: Lord Owen, just to reinforce Lord Archer, to say thank you for your time in coming today and all the evidence you have provided to us. It has been extremely helpful.

I am just asking your opinion on how you believe there might be closure for the haemophiliac community over this issue, including those who are widows and their dependants. Would that be an issue of recognition from government, restoring trust, an issue of preventing this issue occurring in the future? What are your thoughts on that?

A Well, I think we have already touched on it. Some of these issues relate to what was the climate of the time in terms of public opinion, in terms of transparency, in terms of openness and freedom of information and things like that. I believe this committee is doing great work, but I am sure you are the first to admit it would be much better if this was one with the full authority of government behind it.

THE CHAIRMAN: We are very conscious of that.

A And I hear that there is going to be a serious inquiry in Scotland with the resources of the Scottish Health Authority, which I very much welcome. I think you will find that there was less of a problem in Scotland.

But I am not sure you can ever get closure. The constituents who I was involved with are now dead. The compensation scheme, well it was a fight to get it in and it has worked, but of course a lot of people do not feel it is generous enough. Then there is always the

argument of, should it be retrospective? These are difficult questions and I think you have to recognise that money is difficult to get -- I do not know. I am not sure I know how to get closure on it. I do not think you ever do get closure on these things. But a feeling that people have tried, the experience in truth commissions and things like that in different parts of the world, seems to me to indicate that the mere attempt to try, even in these circumstances, this inquiry will do good.

MR MEHAN: Thank you for that.

A I will return my documents to my own library at Liverpool University. You have had them and the inquiry have had all of them.

THE CHAIRMAN: I think we have copies of all of them, thank you.

A And I will put my own evidence into the library, so it will be at Liverpool University and people are welcome to use it.

THE CHAIRMAN: Thank you very much. Is there anything else you think we have not asked you about?

A No. I hope you get to the bottom of it.

LORD ARCHER: Thank you. We are most grateful, thank you very much.

MR DAVID AMESS (called)

THE CHAIRMAN: Right, Mr Amess, you are the Vice-Chair of the Conservative Health and Social Services Policy.

A I am for my sins, chairman.

THE CHAIRMAN: For your sins. I suspect it may have been something which was visited upon you. We don't have a statement from you, so we would be grateful if you would just tell us ...

A The first thing I would like to say, Chairman, is I cannot promise to be as interesting as your previous star witness, but I will do my best. The second thing is, I have suffered from hayfever as a child and I was told that I would grow out of it. Well, I have actually grown into it, so I apologise if my voice is not as clear as it normally is. The third thing I would like to do is to congratulate you on this inquiry. The thing that immediately struck me as a member of the Health Select Committee is, sadly our committee hearings no longer attract the attention that they once used to. Here we are in a very well heated room and that is because of the number of people here. I think you should be congratulated in conducting this inquiry.

Following on the remark from --

THE CHAIRMAN: The heating in the room incidentally, you probably discovered, is because, owing to an error which

no-one has quite traced yet, there was a double booking of where we normally sit, so we had to come here.

A I understand. Following on from the point that Lord Owen mentioned, I received my Health Select Committee papers this morning, and I understand that the new Secretary of State for Health, Mr Alan Johnson, is now going to make himself available to our committee on the afternoon of Monday, 23rd July. As long as I can be there, never mind what the chairman wants me to ask and what he does not want me to ask, I certainly will raise this issue.

THE CHAIRMAN: Thank you.

A Now, I am the Chairman of the All Party Hepatology Group. As you will know, chairman, Members of Parliament do not always lead issues, we tend to respond to them. This All Party Group, frankly, was set up because of constituent concerns that the government of the day was not really treating this issue with the urgency, and perhaps seriousness, that constituents who were affected by Hepatitis C felt that it should have been dealt with. It is an excellent committee.
I believe you will be hearing from one of our inspirations later today, I see in your list of witnesses, and by and large we are an active group, and I think have managed to make some sort of difference.

Recently we had a meeting in the Jubilee Room next door, where Anita Roddick came and spoke to us and all I will say, in this era of celebrities, is her testimony was powerful.

THE CHAIRMAN: I think we may be asking her whether she would like to give evidence to us.

A I got the impression that she is very happy to be proactive on this issue, and whereas they might not listen to boring Members of Parliament like myself, they might listen to Anita.

The final thing, Chairman -- before I shut up, because like all MPs I am going on for too long -- what I would say here, so far as the government's response so far is concerned, is our group has issues with the delay in producing a comprehensive strategy to tackle the disease. We have a real issue as far as that is concerned. We do not feel that there is a comprehensive strategy. We feel that there has been a failure --

MR MEHAN: Sorry, just to interrupt, Mr Amess, when you refer to "the disease", are you referring to Hepatitis C?

A Yes. Sorry, I should have said that at the start. We feel there has been a failure to ensure that primary care trusts are actually implementing the government strategy, such as it is, and I know that my colleagues

on this all party group feel that, because we are all busy people, it would be wonderful if we had the resources to get a hold of this issue to ensure that there was a really comprehensive undertaking survey to find out what primary care trusts are doing on this issue. We have attempted, with limited resources, to get a feedback, which I will gladly, if we have the time, give you a response to.

Finally, chairman, we feel that the raising awareness campaign has been poorly funded, relatively, and has been ineffective. I mean, I could go on, but I will not.

THE CHAIRMAN: Well, thank you very much. Could I just ask you about three of the things that you have mentioned. You talked about a comprehensive strategy?

A Yes.

THE CHAIRMAN: Could you give us some idea what a government might do that is not being done now?

A Well, as we all know, Hepatitis C was discovered in 1989. There was no standard testing for the disease in either patients or blood products until two years later.

Now, the government acknowledged the public health risk when they commissioned a Hepatitis C strategy for England in March 2001 and at the end of that year we were promised that there would be action. But

unfortunately, the strategy itself did not appear until August 2002. So already the committee which I lead regards there has been delay, which, given the frustration of the people who are concerned about this issue, has not helped at all.

A comprehensive action plan was actually promised within months, and it is there for the record, but it was not published for two years. Now, by any count, that just is not good enough. A few months, and it took two years. We all know, chairman, there has been changes of ministers, changes in terms of priorities for the Department of Health; two years' delay my committee feel was unsatisfactory, so we did not get the strategy until July 2004. The All Party Hepatology Group feels that the government just basically has shown a complete lack of urgency in dealing with the strategy.

As well as being late, the action plan is, I believe, woefully short on desired outcomes, or a timetable, or indeed any other measure by which its implementation could be judged. It seemed to me that it would have been an obvious thing to have done, and the noble Lord Owen referred to what was going to happen in Scotland. Well, the Scottish Hepatitis C action plan was launched in September 2006. Within the government's plan for England and Wales, there is no inclusion of

incentives for primary care trusts to implement it, no incentives at all, and certainly no penalties if they choose not to. It is a central government directive with little follow-up, monitoring or analysis.

So I think, chairman, as far as I am concerned, it is just an aspiration with no teeth. It is very disappointing, considering that it took two years to come up with it.

THE CHAIRMAN: I was just wondering whether you could give us some practical examples of the strategy. We, for example, have heard a great deal of evidence, certainly that in the past people were given no counselling. They were just told bluntly that they had what might then have been called Hepatitis C, or might have been given some other name, but they were given no counselling and no help. Is that the kind of thing you had envisaged?

A You have got it in one, chairman. There was just no detail as to how this particular issue was being dealt with. No backup, no support, no analysis of where the expertise would come from throughout the country -- we don't want a postcode lottery as to who would be given help and who would not be given help. I think, frankly, it ended up like a knee jerk reaction where, "we said we would do something within months, let's cobble the thing together quickly", but there is absolutely no substance

whatsoever to it.

The report on the government's Hepatitis strategy I think should be highlighted with the delay in producing the strategy to tackle the disease; failing to ensure primary care trusts implement government strategy once finally produced; an ineffective awareness raising campaign; lack of NHS investment in the hepatology sector; and a failure to prioritise this issue.

The committee felt, chairman, that there was just no detail behind the strategy at all, and I think you will be hearing from Mr Gore later that we did make detailed recommendations as to what the strategy should contain and, for whatever reason, it just seems to have been completely ignored.

THE CHAIRMAN: Do you have a copy of those recommendations?

A I do not have it with me right now, but your secretariat will certainly get a copy of our recommendations, and then you can quite clearly see how they were not acted on at all.

THE CHAIRMAN: Yes, thank you. We heard from Dr Owen a few minutes ago that there was a fairly tight-knit community of specialists in this field. Have you heard from them? Do you get the impression that they were pressing the government for action on this?

A Most certainly. We don't have a huge expertise in this

country on this particular issue, but those we have the All Party Group has been in contact with, and they have shared with us their frustrations in terms of the government's reluctance to engage in a meaningful debate about this issue and no doubt, if you are not already hearing evidence from some of these experts, you may eventually have the time to do so.

THE CHAIRMAN: We hope to, certainly. The other thing that I would be grateful if you could develop is the primary care trusts. You rather gave the impression that the government is not exactly encouraging them. Is your finding that they themselves are not treating this matter with much urgency?

A Chairman, there is a great deal that I could say about primary care trusts generally, because I served on the committee that created these animals, and only referred to my own primary care trust when I was invited to meet the chief executive last Thursday and at the end of the conversation she told me she was leaving and they had not been able to attract a replacement. So we are without someone for months, and this is quite a big area in Essex. I understand from colleagues that this is not an isolated case; that there are staffing problems with primary care trusts.

But if I could -- and I will gladly leave the

committee with the evidence here. Our committee tried to engage with the primary care trust, we sent out a questionnaire which included a set of ten criteria against which primary care trusts could be measured. The results confirm the anecdotal feedback received from healthcare professionals, voluntary sector groups and patients, namely that most health services in England have failed to act on the action plan. Overall 63 per cent of primary care trusts responded to the group survey, which frankly was quite good -- that was higher than we had anticipated -- but only 16 primary care trusts are actually implementing the action plan. 107 primary care trusts are taking a little action, and 68 primary care trusts are doing absolutely nothing. So, chairman, this is dreadful, because the primary care trusts are the driving vehicle in healthcare delivery generally and the fact that we have huge numbers doing nothing is very disappointing.

Forty-six per cent of hospital trusts responded that patients had delays of more than three months for a National Institute for Clinical Excellence approved treatment, or had it deferred to the next financial year. Again, dreadful, really. This was due to staff shortages. Thirty-eight per cent said it was due to staff shortages. Budget or contractual problems

amounted to 51 per cent, and delays in accessing facilities such as liver biopsy, 49 per cent there. Some hospitals reported waiting lists for treatment of more than 100 patients. Waiting lists for treatment of more than 100 patients.

Results were widely variable across the country, meaning that Hepatitis C care remains a matter of chance, entirely depending on where a patient actually lives. But I am sure, chairman, that is not really a great surprise to your good self. But it is shocking.

THE CHAIRMAN: It is certainly something which needs to be addressed. Yes, thank you. Judith?

MS WILLETS: So the implication is, it is something to do with the sort of rotten state of the Health Service, is that what you are saying? It is something to do with lack of money, with lack of staff?

A This government has poured huge resources into the health service.

MS WILLETS: Absolutely.

A No-one could deny that. I am puzzled that, given this huge amount of money, the return is so poor. Now, as we all know we have a "new" government, and I will be hearing on Monday week from the new Secretary of State for Health how he intends to turn this round, that the outcomes seem to be so poor.

But I do not know, perhaps Members of Parliament are at fault here, that we should have rallied on this particular issue much earlier. But now we are focused on it, I think it is a wonderful opportunity to get the new Secretary of State for Health to prioritise this as an issue.

So I would not like this to be a battering ram, because we have a rotten government and they are not doing well in the Health Service, but I hope that, given that the real quality witnesses that you have assembled for this Inquiry -- fabulous really -- that I intend to make sure from the House of Commons' point of view that the government takes your findings seriously. I am going to ensure that you, Mr Chairman, have not wasted your time at all in conducting this independent inquiry.

MS WILLETS: Can I just ask one other thing. In addition to your committee looking very much at what needs to happen in the future in terms of a strategy, to what extent has it looked retrospectively at the history of the disease? It used to be non-A non-B, it is now Hep C, and it did not used to be considered to be particularly serious; we now realise it is absolutely cataclysmically serious. To what extent have you looked back at that? We have heard quite a bit of evidence about how doctors were at the time and how they did not necessarily discuss levels

of risk with their patients, but we have also heard from many people that they simply were not told they had Hepatitis C at all, or perhaps they were told after several years' delay, and obviously implications around that are very serious. I wondered what your thoughts were on that and what your committee had been delving into?

A We have had evidence from long time sufferers, we have seen a film logging the history of this, we have heard from Lord Jenkins, when he was Secretary of State for Health, his particular take on the issue.

I think our committee is aware of it, but I am going to be frank with you, members of the House of Commons I do not think have fully appreciated how serious, disappointing and disgraceful all this is, because it should never have happened, if things had been dealt with differently. I do not think there is widespread understanding throughout all members of the house now. You, chairman, will know only too well that Members of Parliament are not experts in any issues, we are all amateurs really, and some people specialise in health, some people in education. But the one thing we should all specialise in is representing our constituents and in every constituent there is going to be someone who has suffered as a result of what went on years ago.

So I sense from your question that perhaps we are criticised in looking back, but unless we consider history, how can we deal with the situation at the moment, learn by our mistakes, and make sure that this never happens again? I would never be party to a cover-up, so I am absolutely delighted that these documents now are surfacing.

I heard Lord Owen say, "Why is it that the civil servant who gave these instructions should remain secret, because perhaps if we hear from that individual we will understand better why it happened." We cannot sweep this under the carpet, because people are suffering now, and their lives are every bit as valuable as the next person. They have a right to know why this was allowed to happen and how it is going to be addressed in the future, and not just sort of some cosmetic strategy which has no detail in it whatsoever.

MS WILLETS: Thank you.

THE CHAIRMAN: You did say that there had been something of a change in the attitude to this, I think. We have heard that in the 1980s, it was not regarded as a very serious matter because people had not grasped the implications of it. Do you detect any change in the way that this is now approached by the authorities, authorities including governments and so on?

A I think the reason there is a change is quite simply because of pressure. Everyone feels so strongly on this issue that I think those who are in a position to do something about it realise that we are not going to go away.

Now, we all know about short-term-ism, what is a big issue on Monday you do not hear about on Tuesday, but I have been impressed that we have some very committed, dedicated individuals involved in this campaign who are using the right processes to ensure that this issue is going to get the due care and attention that it rightly deserves. So whether it be in Parliamentary terms, with photo opportunities, presenting petitions to number 10 Downing Street, or holding functions in the House of Commons, meeting constituents with concerns, I think that the force is gathering momentum and that actually is changing people's awareness.

Now, we can all think of the AIDS campaign when I think Norman Fowler was Secretary of State, and we had the tombstone advertisements, and that certainly got the public's attention to that issue. The thing that we are discussing this morning, it is not quite so easy, really, to heighten public awareness about it. But I do think, given that we have someone like Anita Roddick involved in this issue, that that helps and I hope that

more and more people will come forward.

THE CHAIRMAN: Thank you very much, Mr Amess. Is there anything else that we have not asked about that you think we should?

A No, I think I would just be repeating myself. I would just say again, chairman, I congratulate you on holding this inquiry, and I will certainly be raising this issue with the Secretary of State, because I do think that the government really should be doing what you are doing now.

THE CHAIRMAN: Thank you.

(10.52 am)

MR CARRUTHERS (called)

THE CHAIRMAN: Thank you very much for coming, Mr Carruthers. How would you like to do this? Would you like to make a statement and then we can ask any questions which occur to us?

A Well, I would like to thank you first of all for holding this inquiry and giving us this opportunity. I would like to read this statement, but if you wish to interrupt, please feel free to do so.

THE CHAIRMAN: Yes.

A I will start off by telling you who I am. I am a haemophiliac with Christmas Disease, which is Haemophilia B. My condition is diagnosed as severe,

although historically I have been mild, meaning only needing cover of Factor IX -- whereas the other Haemophilia A has Factor VIII, I have Factor IX -- a blood clotting factor which is less than ten per cent in my system. It was originally less than one per cent, it is now actually rising. I only needed the clotting factor for dental reasons or emergencies, which are very rare.

Now I lived in the USA for a couple of years, returning to the UK in 1982. Now just previous to my return I had a tooth extracted. It was explained to me that it was more dangerous to give a blood product than to extract the tooth without cover due to a viral infection -- and that was 1982 -- if required, post extraction cover being available.

In 1989 I again required dental work, now in the UK. I was to attend the RVI, Newcastle upon Tyne, on GRO-C 1989 -- I remember the date because it was my 40th birthday -- for an injection of Factor IX. I requested that, as in the States, it was only standby. The doctor objected, not on clinical grounds, but stating it would require a dental surgeon to come from the dental hospital and an overnight stay for me for observation.

THE CHAIRMAN: Was this because you did not want to use that

blood?

A Because of what the doctor had said in 1982 in the States, about viral infection. I would like to make clear I was totally unaware that haemophiliacs had died of HIV, even though I was a haemophiliac myself.

THE CHAIRMAN: I just wondered why he insisted there should be a dental surgeon there. Was that standard practice?

A No, he said I would have to stay in the hospital, to bring a dental surgeon over to do the operation in the --

THE CHAIRMAN: Or because you were unwilling to have --

A Because I was unwilling to have the clotting factor.

THE CHAIRMAN: Yes, I see.

A But the dental hospital, incidentally, is in the same grounds as the RVI, so it would not have been a great distance for them to come anyway. Nonetheless, after the consultation I thought we had agreed that that is what would happen; that the dental surgeon would come over and I would stay in hospital.

Anyway, after this consultation I went to Iraq to work. I was in charge of projects over there. On my return, I attended the hospital to be informed I was to be given Factor IX despite the previous consultation, and then go to the dental hospital for the extraction. In my opinion this proves that it was given not for my

safety, but for the convenience of the National Health Service and to save costs, because the doctor was obviously aware of the viral problem, because I mentioned it to him.

Three or four months later, while again working in Iraq, I became ill, sweating and delirious. On my return I revisited the RVI, by which time I had pains in the liver region, chest, head and yellowing of my eyes and skin. The haematologist asked if I had had an affair whilst in Iraq. This I thought was an inappropriate question and, since then, finding out he was aware of HIV and Hepatitis non-A non-B viruses, totally out of order.

Blood tests were taken and I was diagnosed with Hepatitis C. Diagnosed with Hepatitis C in 1989, not in 1991, like the previous speaker just said. 1989. I was diagnosed with Hepatitis C.

THE CHAIRMAN: You were told Hepatitis C? It was not given some other name?

A Not non-A non-B. I was told I was the first person in the north of England, and possibly in the country, to be diagnosed with Hepatitis C. It was actually Hepatitis C.

A year later I was offered a biopsy -- this is not in the notes -- a year later I was offered a biopsy.

I said, "Why would I need a biopsy? You have no cure for Hepatitis C. Are you trying to tell me you do not know if it is Hepatitis?" He said, "We do know, we definitely know it's Hepatitis C." I said, "So, you want to drill a hole in my side, take a piece of liver to prove something you already know and you have no cure for?" So I refused the biopsy. Now they will not give us one, but that is because I am a haemophiliac. You work it out.

Anyway, due to the time scale of the cover in May and subsequent illness I believed -- and still do -- that the product I was given in May of 1989 was contaminated. I checked with BPL, the suppliers of the product -- I actually wrote to them, and they wrote back -- they were never informed of any products being contaminated in 1989, I believe in 1988 as well. So it was never reported to them that it could have been that product.

When I mentioned this to the hospital they said, "Oh, you were probably infected earlier". It is always possible, but I doubt it. All the products I have received -- according to the RVI records, the only hospital where I have had blood products -- are British.

The genotype of the disease is genotype 1. This was, at that time, predominantly American. This raises

the questions of how many haemophiliacs, having only British products, have this genotype and why.

Since then I have struggled to continue working, dropping my aims from project leader to supervisor to service engineer, and eventually maintenance electrician. My earnings have also decreased in line with my ambitions. My first change of occupation was to a company that produced metal decorating machines as a field service engineer. I still achieved a position of technical support manager, losing this position when I started reacting to the chemicals used in the process. I did not realise what was causing it.

THE CHAIRMAN: Could I just interrupt? Is this because you were losing time through illness or because you had not the energy, or?

A Well, I was reacting to chemicals, so I was saying that I could not visit companies that used the chemicals, and they said, "That is part of your job." It makes you very -- it was making me very tired. Basically, the liver just was not getting rid of the toxins. But I did not realise it was that because the doctor had said it was not, basically.

The medical information I received about Hepatitis C was, at best, sketchy. When I told a haematologist I was suffering pains in the liver region, his comment

was, "This just proves you are mortal". I was becoming less and less able to do ordinary electrical fault finding, which was the thing I was best at, at that time, used to be.

It was at this time I sought information via the internet about Hepatitis C. At first I believed that the conversations between sufferers were being exaggerated -- they were about people dying and all the rest. This, I now realise, was denial on my behalf. One day it sank in that I was suffering the effects of Hepatitis C, including brain fog. It was as if my world had collapsed. I sat on my own and thought, "What the hell have they done to me?" This is not the best way to find out about the effects of Hepatitis C.

I eventually contacted Haemophilia Action UK, where the bravery of Peter Longstaff, who died two years ago, gave me hope to go on. Carol Grayson gave me more information and pointed me towards more information in one afternoon than the National Health Service had supplied in all the years up until then. I then heard about Interferon and Ribavirin treatment. I went to the hospital and asked about it and I was told I would have treatment in the April, in the new financial year. When I heard nothing, and after repeated requests for information, I decided to contact my MP and newspapers

in the area. I was eventually promised treatment at the end of the year to start the following January. One of the local paper's articles stating that I was refused treatment earlier on also carried a story about an inmate in prison who was complaining regarding the attitude of doctors whilst he was having treatment. I thought, "Maybe if I get myself arrested then I could get treatment."

Only after the first treatment, which was overseen by the haemophilia department -- no hepatologists at all involved -- did I insist on a liver specialist in a different hospital, as the attitudes of the head nurse and doctors were not very pleasant. The care was far better at the Freeman, also in Newcastle --

THE CHAIRMAN: We do have a practice here that we do not mention specific hospitals or specific people as far as possible. Otherwise it would entail taking so much more evidence we would never get around to reporting.

A I have omitted all the people's names. However, since then I have moved to Andover and my treatment is in Basingstoke. There is only one hospital there. The haemophilia department and specialists there are excellent.

My last treatment was halted when it was found I was suffering from drug-induced fibrosis of the lung, a side

effect never explained when I started treatment. Actually, the rest is just about the fact I have taken a cut in hours where I work and a drop in pay, and I am now seriously thinking of retiring on health grounds if I can do it. That is it.

THE CHAIRMAN: Yes, thank you very much. That is very clear.

MR MEHAN: Have you received any sums through the Skipton Fund?

A Yes.

MR MEHAN: When did you get that and how much was it?

A It was 20,000, the first payment.

THE CHAIRMAN: It remains to be seen whether, hopefully, you won't qualify for the second payment.

A Yes, hopefully. As I say, the liver function test is normal, but because they can't do a biopsy, that's as far as they can go.

MS WILLETS: They want to do a biopsy to see what further damage had been caused to your liver?

A That was in the early days, yes.

MS WILLETS: But your refusal then was that you can't do anything about it anyway, but I assume they were trying to find out if you had any additional complications on top of your Hepatitis C?

A I would imagine so.

MS WILLETS: So you think you were the first person to be diagnosed with what was then in 1989 identified as Hepatitis C?

A That is what I was told, yes. The first person in the north of England, they said, and possibly in the UK.

THE CHAIRMAN: Okay, thank you very much, Mr Carruthers, we are most grateful.

(11.05 am)

MRS DELIA RYNESS-HIRSCH (called)

THE CHAIRMAN: Good morning Mrs Ryness-Hirsch. Would you again like to just make your statement or would you prefer me to put questions?

A I would like to make my statement and you can stop me if there are questions you would like to ask.

THE CHAIRMAN: Yes?

A So first of all I am going to be speaking on behalf of myself and my husband Dan, so when I say "I", I mean we, and it is divided into two sections, one on HIV and one on recombinant.

In 1976 I gave birth to non-identical twin boys, one of whom was discovered to have spontaneous haemophilia. He was assigned to a children's hospital in London. First of all let me explain that my husband is American, and we had met and been living in San Francisco in the 1960s, and my closest friend, who was

English, remained there because she too married an American, and still lives there.

From 1978 onwards, I began receiving information from Irene about the problem with the blood there. She is a very diligent friend, and she had picked up that it there were some problems there. This is 1978. She began sending me articles and information -- there was no email then -- and I took them to the hospital continually. I had continuous discussions with the doctors in the haemophilia unit there. My views were absolutely ignored, they were not given credence, and I was treated in a very off-hand manner. Their assistance to my son was perfectly okay. And this was only the beginning of my interaction with the medical profession, so I was not as militant as I have become.

In 1980 there was a policy that when children became four years old they were switched from the English factor onto American factor. When we arrived for our son's first treatment, I created such a furore there, such a furore, talking about the articles, talking about that there was something wrong with the blood, and therefore with the blood products from America, that I had lived in America, I had full knowledge of where the blood came from. Certainly in the 1960s in San Francisco people sold their blood freely, and I know

that later on you have the director of the Arkansas prison film. None of it was obtain into account, but because of the furore I created, they decided to leave our son on English Factor VIII.

After the Panorama programme that publicised HIV, which I think was at the end of 1984, a discussion of heat treatment for blood products was commented on in the papers. In a leader article in the Guardian on January 21st 1985, which discussed heat treated -- there was an article which discussed heat treated Factor VIII, and I have supplied the Inquiry with photocopies obtained from the British library newspaper archives of all these letters.

I wrote a letter to the Guardian refuting or explaining further what I thought had happened in terms of the Factor VIII, and it was published on January 23rd 1985, written under my sister-in-law's name because of the ugly reaction already starting against children who were identified as haemophiliacs. And I talked in the letter somewhat about heat treatment and somewhat about the fact that I had been bringing all this information, that I had tried to initiate discussions, that I had tried to take it further and had been stonewalled. The letters editor of the Guardian at the time was a friend of ours, and he allowed me to do it under a false name,

which they don't normally do.

Some days later there was a response letter from the head of the Haemophilia Department if the hospital, refuting what I had said and saying that they had never had any information, that they had never been informed, et cetera, et cetera. I want to say --

THE CHAIRMAN: Not been informed of your anxious or not been informed --

A Yes. Of the articles, of all of the things. I want to state as well at this time, that our GP who I have now spoken to recently, we still have the same one, is prepared to collaborate it. My sister is a member of Parliament and is prepared to collaborate this. This all really happened.

Anyway, shortly after his letter appeared in the guardian, the head of the Department rang my husband and I at our business. Now theoretically he should not have known who the hell this person was, it was under my sister-in-law's name, this letter, there was no reference to my name, I had written under Julia's name. But he knew immediately who to ring, of course he knew immediately who to ring, because there was only one person in the department in the 1980s who was having this enormous fight, from the 1970s onwards.

He asked for a meeting with us. We went up to the

Children's Hospital and we had a meeting. And he told us that they had given a test to all the children in the Haemophilia Department at that time, and our son was the only one under 9 years of age who did not have the virus. He also said that heat treatment would not be available -- I think this was in the January we met with him, of 1985 -- he said heat treatment would not be available for a few more months, what would we like to do about that? Did we want our son immobilised et cetera et cetera, and we asked for some time to think. And it came to me while we were at home that if he did not yet have the virus, it meant that all the treatment that he had had up until now was clear, and you always had ends of bottles et cetera et cetera, and we went back and said to him, "Right, if you can get from BPL all the ends of the batches that he has had for the past few years, and there is enough to see him through, in this case they will let us mix batches and use that." And that is what happened until heat treatment arrived.

MR MEHAN: When you refer to the virus do you mean Hepatitis C?

A No, I am talking about HIV now. At that time it was non-A and non-B, and we were not thinking about that.

MS WILLETS: Can I just ask something?

A Yes.
MS WILLETS: Your son was the only one that was not HIV positive?
A Yes, in this small group of children.
MS WILLETS: Was there any comment on how the others had been infected, or would they not have made any comment to an individual?
A No, there was no other discussion at all.
MS WILLETS: And I do not suppose you know what they had been given?
A No, no. But I am assuming that if their parents did not cause an uproar that they were on the American one.
We decided to take him away from this hospital and take him to a London hospital. I have enclosed a copy of the relevant note at the first meeting at that hospital from the clinician who met him, saying that this child has never been treated with anything but NHS factor due to Mrs Ryness-Hirsch's efforts and anxieties. At this point the children's hospital refused to give his file.
THE CHAIRMAN: We are not naming hospitals.
A I did not, did I?
THE CHAIRMAN: No, I take your point.
A The hospital refused to give the file to the new hospital, which, I mean, we all found extraordinary.

And one day again at work we had a phone call from the sister at the unit at the original hospital saying, "If you and your hospital come round right now, I am giving you his file to take", which we did. But before we took it we had a look in it, and on the date, when he was four years old, that they wanted to give American treatment, written across the page was "neurotic mother". And that exactly sums up the attitude, the respect and the thoughtfulness with which we were treated and our anxieties were treated.

So let me go on. So there is no question in my mind that, at the time all of this was known about, if I, who knew nothing about medical matters, but was a reasonably intelligent person and understood that there was a problem in the blood, then I am absolutely certain clinicians knew. And it follows through that somebody in the political realm knew, and it was a matter that was known and was ignored. And I totally agree with -- I have not been to this Inquiry, but I have been following it on the net -- and with the people who say that clinicians have treated both the haemophiliacs and their families with contempt, on many occasions. There are exceptions, but they are few and far between. Mostly it was a lack of information and, as you will, hear a lack of pastoral care.

THE CHAIRMAN: Could I just interrupt for a moment?
A Yes.
THE CHAIRMAN: If you had been offered a choice, if people had said, "Well, we are not self-sufficient in blood, we don't have enough blood products from this country. It is either a matter of not giving him the treatment or treating him with the American product", what would have been your choice?
A That is really difficult to say. I mean, I think probably I would have had to have let them treat him, but there was, I precipitate -- they were -- well, I do not know that I would have done. Why should he have been? Why would --
THE CHAIRMAN: It would be a very difficult question.
A It would be a hugely difficult question, but fortunately for that one I did not have to make it. So I can say I do not really know what we would have done.

Right, after this our son was diagnosed -- his non-A non-B was revealed as Hepatitis C, and in common with other people it was done in a letter, very little was discussed about it, he -- that is a whole story in itself, but let me say again we found the clinicians very, very resistant to involve us in choices. And in the end I had to ask them would it be possible for us to consult -- have a second opinion. And we were very,

very fortunate in finding an eminent professor who was a really -- who is a real human being, and absolutely the top in his field, who showed the sort of care and understanding, as well as being brilliant, that is required when you are treating patients with any sort of serious illness. And he has, although he is not involved in our son's treatment, he is always available for us to ask any questions we want and has been an enormous help and comfort to us.

However, about this time, I heard about recombinant and I start agitating for our son to have it, I thought he had had quite enough, I did not see any reason why he should not get it, but of course there were loads and loads of reasons why he should not get it.

MR MEHAN: Just to interrupt again, when you say about this time, can you be specific about a particular year or period?

A I think I first started agitating on recombinant in something like 1990, 1992. But it was impossible and it was still in an experimental stage, I cannot remember.

However, in 1997, our son went in to pick up some treatment, he was pulled off of reception, taken into a room and told that a batch of treatment that he had had had been donated by somebody who died from CJD. That was the end of the story. He left. We got a hysterical

phone call. We tried to find him, we could not find him. Eventually we did, we comforted him. We tried to do everything we could for him. And it was and it is a nightmare.

I do want to express at this point something I am sure that everybody in this room is aware of, that when you take on the medical establishment, you are dealing with the very people who hold your loved one's care in their hands. And that is a very, very frightening situation. In the end, I decided that I had no choice but to be brave, that these were people, they were as liable to failure or success, but they had a right, they had a duty to be human beings. I have found many are not human beings, and perhaps that is a medical requirement in some people in order that they can conduct medicine. But I have not found many clinicians to be diligent, or honourable.

Anyway, we demanded a formal apology, we --

THE CHAIRMAN: Sorry, could I just ask this, you asked for an apology because your son had been told that he had contracted the disease?

A In such a brutal --

MS WILLETS: The manner of it.

THE CHAIRMAN: That is what I was going to ask.

A Absolutely. Absolutely. As far as the exposure, that

was a campaign to come later. But as far as -- to tell somebody something like that, when you are hearing all this rubbish in the papers about a new caring society, and how they are putting pastoral care and they are doing a psychological sort of protection. And to tell somebody something like that and just send them out -- first of all, to pull them off, absolutely shocking, absolutely unforgivable. And when we met with the doctor concerned, he apologised, because obviously the hospital had forced him, but you could see he did not know that he had done anything wrong.

THE CHAIRMAN: But your complaint is about the manner in which he was told?

A Yes.

THE CHAIRMAN: Not that he was told?

A No, I think it is right that he was told. I mean, it is very hard -- I do not think I even considered that. I do not think it is wrong that he was told, even though it obviously has left him living in very uncertain times. But the manner of it was absolutely brutal. Brutal.

So then in 1998, I started a campaign to try and get recombinant for our son, and basically all haemophiliacs. And I have listed to the Inquiry letters I wrote at the time our local MP was -- am I allowed to

mention an MP's name?

THE CHAIRMAN: I do not suppose she would mind. It was Barbara Rose, was it not?

A Yes, and our local MP now is my sister, so I feel I have a little more clout, but not much I can tell you. A letter to Baroness Hayman, a letter to Sir Philip Hunt, a letter to Alan Milburn. In response to all these letters, a bland letter from the Health Service Directorate saying practical nothing.

Then I had a long involvement from 2000 to 2003, which is not in my notes, with the primary care trust, and I endorse everything that the MP said. It was absolutely shocking. I wrote at least 50 to 100 letters, and they had no interest, they lost documents, they could not have been less concerned.

I talked about the cruel, unusual punishment, which is the phrasing in the Human Rights -- the European Human Rights. They did not think it was cruel and unusual that our son had been infected, however many years, 15 years after it was first known that there were blood borne viruses. So they did not think it was bad that he had been exposed to new terrible things. And they felt it was perfectly all right for him to go on being exposed to new terrible things.

And I want people to think about very clearly the

fact of what it is like to make somebody use something which in a sense links with the Chairman's question, that is a life saving product which may kill you, which he has had to do, and which he has done, and with which he is paying the price.

We also instituted a private judicial review for three years, which we paid for, very expensively, and went nowhere, through a firm of solicitors. He was finally given recombinant treatment on 21st August 2003.

One of the results has been of him being so frightened to use his treatment for so long, and he was frightened to use it, is that he has severe damage to his ankles, which obviously impairs his quality of life as well. There have been many --

THE CHAIRMAN: That is from the haemophilia presumably.

A Yes, it is -- no, no -- yes, it is from the haemophilia, but it is because he was forced to use treatment he knew probably was infected. I mean, to this day they have no reason to believe that non-recombinant Factor VIII is free of CJD. There is no way. They do not know when people give blood to this day. They don't know who is going to get it and who is not.

THE CHAIRMAN: You mentioned the pain in his ankles. I think I want to be clear about this. That was from the initial haemophilia was it?

A Yes, but it got much, much worse, because he stopped treating himself whenever he could, because he was frightened.

THE CHAIRMAN: Because he stopped treating himself?

A Yes. He tried to only do it rarely. And I heard stories of people trying to share their recombinant when they had got it already. It has placed the haemophiliac community in the most terrible position. They are still in the most terrible position. And I am not talking about compensation or recognition or anything. For those who are not yet on recombinant, they still have this fear. There are other viruses that are in the blood; anything that is in the population is in the blood. And the Health Service have no way of clearing those viruses yet. They can do the Hep C and the HIV from heat treatment, but not in other ways.

THE CHAIRMAN: And the people you are talking about don't have access to the recombinant?

A Some don't yet.

THE CHAIRMAN: Is that the point?

A Yes. And they have to think, every time they inject themselves, think about what is in the Factor VIII.

Right, where am I? As far as I am aware, there has been official enquiry in many countries into the scandal, even resulting in prison sentences in some

places. And, in fact, I read, today I think, in the paper, that the Chinese Minister of Health was executed this week, because he allowed contaminated products -- nothing to do with haemophilia -- which killed five people. Well, I would not agree with that, but the fact that it has gone completely unchecked and unexamined until now ...

The fact that haemophiliacs in particular have been exposed to these dangers and no-one is prepared to allow even for the possibility that they knew about it, it is a complete horror. No responsibility, no acknowledgment. I am certain over the past months, you have heard time and time again about the misery of these events -- that it has brought into many people's lives. I am not going to say any more. That is it.

THE CHAIRMAN: Well, thank you very much. We have a statement from your son.

A You do.

THE CHAIRMAN: Does he wish to give evidence?

MR MEHAN: Would you like to read it?

A I do not mind, if you would like to read it or I can read it.

THE CHAIRMAN: We are in your hands. If you would like to read it or he would like to read it?

A Well, he is not here, he didn't want to come.

THE CHAIRMAN: Well, if you simply want us to read it, we are -- we can?

A. Yes, yes, it was for you to read, to just know his opinion.

MS WILLETS: It is almost difficult to start with such a catalogue of horrors.

A I feel the same.

MS WILLETS: In terms of recombinants, I am perhaps not fully up to speed on this, but it is not available for everyone at the moment. Is that dependant upon where you live or which health service is treating you? And what are your views on that? Because if there are still so many unknown potential risks with Factor VIII, then one would have imagined that it would be a priority to get everyone onto recombinant as quickly as possible, which clearly has not happened; and I do not really understand why. Well, I probably do actually, but I will ask you the question.

A I have to say, I am not completely up to speed on that. I know that when it was introduced in 2003, that it was introduced -- or 2002 -- on an age-related, so they would go upwards in age supplying it --

MS WILLETS: So they would give it to the younger people first?

A Well, younger people have been on it for some time.

Anyone who did not have Hepatitis C or HIV or had been exposed to CJD got it. And then finally they were persuaded, and they were introducing a rolling -- bringing it into the community. I do not think everyone has it yet. I do not think everyone has it yet. You would have to speak to the Haemophilia Society, they would have the facts, I am not sure.

THE CHAIRMAN: Thank you very much. That has been most helpful.

A Are you done? You do not want to ask me anything?

THE CHAIRMAN: Unless you have anything, Vijay?

MR MEHAN: Nothing specific. You have been very helpful in providing all the documents and articles as well. Just on that issue of recombinant and the campaign, did that last between 1997 and 1998 through to 2002 when your son was eventually given, in the August of that year, recombinant?

A Pretty much, one way or another.

MR MEHAN: This is a long period of time, it was five or six year?

A It is. But I did not do it all the time, because I had to keep recouping my energy. It is the most awful thing to have to talk about these things coherently when they are so close to your heart. And effectively -- and it is no good to be emotionally overwhelmed by it. And so

every so often I would have to take a break to recoup my energy, get myself stabilised and get going again.

THE CHAIRMAN: You seemed to have worked at it with admirable persistence.

A I learned.

MR MEHAN: Just one other question regarding your son being told that one of the donors that he had received product from had died from CJD, does that worry you? On a scale of one to ten -- every day?

30, 50, 100! on a scale of one to ten. And I also would like to add that not a word has been said about it since that time. We have never had any care, he never had any help from the hospital.

THE CHAIRMAN: No counselling?

A No.

THE CHAIRMAN: Thank you very much indeed.

(11.30 am)

MR CHARLES GORE (called)

THE CHAIRMAN: Good morning Mr Gore, thank you for coming. You are the Chief Executive Officer of the Hepatitis C Trust?

A I am.

THE CHAIRMAN: Would you like to tell us anything?

A I would like to say first of all that --

MR MEHAN: Sorry to interrupt. Charles, if you repeat your

name and your status and position for the record.

A My name is Charles Gore, and I am the Chief Executive of the Hepatitis C Trust. I would like to say, first of all, if I might, that I have not prepared a written statement. This is partly because I am not entirely certain how I can be of help to this inquiry, which I will come back to. What I do not want to do is to repeat a lot of what has already been said in a number of submissions, including the Haemophilia Society's submission, which is very comprehensive. So what I would like to do, if that is all right, is to make some points and then be available for your questions, and then afterwards, from what emerges, send you a written submission. Would that be acceptable?

THE CHAIRMAN: Certainly.

A I also don't propose to talk about specific haemophiliac issues. I think that you undoubtedly have been hearing a lot of evidence to do with haemophilia, and I think they are well represented here and not in need of my expertise. The trust which I run is a patient-led and entirely patient-staffed organisation for everyone with Hepatitis C. That, of course, includes haemophiliacs. But I think what I would like to talk about is people who received infected blood by transfusion and some of the issues that they have.

THE CHAIRMAN: Could I just ask you this: when was the trust established?

A This is another good reason why I am sticking to a slightly different method. We only started operating in the summer of 2001, so well after a huge number of the events involved here.

I would just like to make some points. The first one is that Hepatitis C is not a benign disease, and the original understanding was that it was, and over time that has changed. It is even now being proved to be considerably more dangerous than people had thought.

The latest information I have, admittedly in the Pakistani population in east London, which has largely had infections for considerable periods of time -- up to 50 years -- is that of the people who have had Hepatitis C for more than 50 years, well over 50 per cent have cirrhosis. In fact we are doing a prevalent study in east London at the moment, testing people in mosques and community centres, and all the over-50s who are positive are cirrhotic.

Clearly this is important if that is going to be the end stage of the disease if you wait long enough, because one of the big problems that we have in this country is a lack of organs for donation and there are simply not enough livers in particular. In 2006 there

were 1152 on the waiting lists and only 634 transplants, and that is predicted to increase as a problem.

THE CHAIRMAN: Is that another matter in which there is a debate as to whether we should be self-sufficient?

A No, not as far as I am aware. It is a debate in how to increase the organ donation rates.

THE CHAIRMAN: I see.

A I will come back to this. But there is a government task force looking at this, but in such a slow way that it is very indicative of the entire approach to Hepatitis C, I would say.

One of the other points I would like to make about Hepatitis C as a disease is that we now know that it affects parts of the body other than the liver, and in particular a lot of work has been done recently into the way in which it crosses the blood/brain barrier, and it is clearly linked to depression and cognitive impairment and so on. Even in people who think they are asymptomatic, our experience at the Trust has been that people who have had treatment and cleared it then realise how ill they felt before. One adjusts, particularly if it comes on slowly, to one's condition pretty often. So I just wanted to say, to start, that this is a serious disease with a lot of unpleasant consequences, both in terms of living with it on a

day-to-day basis and in terms of long-term prognosis.

I don't want to get into any kind of fight between diseases, but I do want to stress that currently HIV is becoming much more of a manageable disease, just as we are realising how serious Hepatitis C is and, to be honest, when people become infected, our experience is that patients say that Hepatitis C is their problem; they can manage their HIV. Liver disease is becoming an increasingly important cause of death in HIV infected patients. So I don't want to play down HIV in this case at all, but I also don't want -- sometimes press coverage tends to focus on HIV because it is a much better known disease.

THE CHAIRMAN: It is more dramatic?

A Exactly. Now, the period during which the infected blood and blood products happened -- I do not really want to per se talk about it -- for starters, the trust was not in existence -- but I would just like to mention that in comparison to other countries, what we did is obviously slow here compared to the introduction of -- well, the failure to have a surrogate test, the slowness in which heat treatment was introduced in Scotland, the delay in introducing a screening test here. Now, there may be good reasons for that, whatever, but it is very clear that we were behind other

countries.

I also think we were behind in the look back. This was not started until 1995 -- and I am talking about the English one, carried out to trace people who came forward to donate blood, were found to be HCV positive, and anyone that they had donated blood to was traced.

Now the reasons given at the time by the Deputy CMO were:

"Until recently there was no treatment to offer those who might be identified and it was believed that this exercise would have been technically very difficult."

Now, in the case of an infectious disease, I do not find the argument persuasive that there was no treatment available. Most people do not want to go around infecting other people even if they can't do anything about the disease themselves.

Secondly, the technical difficulties referred to have not been adequately explained to me, and the actual wording is: "we believe that this exercise would have been technically difficult". In fact, they did a pilot and found they could do it and did it.

So we had a four year delay in which there was no look back, and in which infected people could have been identified and that might have stopped onwards

infection. So, again, I think we have been very slow. Even in the absence of treatment, we now know that there are lifestyle changes -- in particular stopping drinking alcohol -- that can make a big difference to disease progression. Now that was not known then, but I think it would have been a reasonable assumption that if you have any liver disease, you probably do not want to be drinking alcohol at the same time.

They only actually traced 1,300 or so patients out of the 4,500 or so they identified as possibly at risk.

MS WILLETS: Why was that, do you think?

A Records, people moved, people died.

MS WILLETS: I was going to say that some people would be deceased by that stage.

A Absolutely. But clearly the longer you leave that, the harder it becomes, so waiting until 1995 is just making the job more difficult.

They have never, to my knowledge, asked newly diagnosed people in that period whether they have donated blood, because the entire look back relied on someone coming forward again for donation and being screened and picked up then. But somebody who had raised ALTs and went to their GP and was diagnosed, nobody said, "Did you at any point give blood in the past?", and try to trace that. So it could have been

better as well as quicker.

Then when we come to what action has been taken about Hepatitis C generally, the French introduced an action plan in 1999 after two years of rigorous research; England in 2004; Scotland in 2006; Northern Ireland in 2007; and Wales, with a bit of luck, this year but, if not, next year. All the action plans were delayed. Just to take England as an example, a working party was set up in the spring of 2001. It was supposed to come up with a strategy by the end of 2001. In fact it did not come out until the end of the summer of 2002. An action plan from that strategy was supposed to emerge within four months, by the end of 2002. It actually appeared in the summer of 2004. So it took three and a quarter years to produce an action plan.

THE CHAIRMAN: Was it actually necessary for the devolved governments to spend a lot of time on an action plan if it had already been done here? I consider there may be some marginal regional differences, but one would have thought that the bulk of the work had been done for them.

A My personal opinion is that it had been done so badly that it certainly needed to be done again. Also, we do have quite a different system now in England, with such devolved healthcare and so much decision-making taken at

PCT level.

THE CHAIRMAN: I see.

A But yes, I do not think there was that much liaison between the various health departments.

As part of the action plan in England, the Department of Health committed itself to raising awareness. Clearly part of this was to identify people who had had transfusions prior to 1991 and get them tested. It started in December 2004, it was very low key, it was done through PR. The Chief Medical Officer at the time, when I challenged him about this way of doing it, said that he thought it was definitely the most effective way.

They did not put much money into it: only about £3 million. This compared, for example, with £4 million to persuade people to eat less salt -- I do not know if you remember the slug -- when actually that is largely a thing for food manufacturers rather than individuals, and £40 million a year to persuade people to switch from analog TV to digital TV. Now whether you think saving people's lives is worth less than a tenth of what you should spend on getting people to be able to watch Eastenders is, I would have thought, open to debate.

It has been very slow happening, and should we have cases like -- let us just take Anita Roddick, who

received a transfusion in 1981 at the birth of her younger daughter and was diagnosed by chance, because she had raised ALTs, in 2004 during a checkup for medical insurance. That is the only reason she was picked up, and she has cirrhosis, and for a number of reasons has been advised against treatment, so that is somebody who will probably need a liver transplant.

Taking another case, someone that we are in contact with a lot, a 19 year old girl whose father had a transfusion after a car accident in the late 1970s and was diagnosed because he started feeling extremely ill, obviously from end stage liver disease, in September 2005. He was dead by Christmas.

So the absolute importance of raising awareness amongst people who had transfusions is clear, but it does not seem to have been noted by the Department of Health. The rate of new diagnoses -- and most of these are not new cases, they are new diagnoses of existing cases -- is running at -- and this is antibody positive, not even chronic, the chronic cases will be about three quarters of this -- is running at about 8,000 a year, and it has been running at that for the last three years, 2004, 2005 and 2006. 2004 was before the Department of Health awareness campaign. So it has had no impact whatsoever.

THE CHAIRMAN: It seems likely then that there are a large number of sufferers now who don't know that they have the disease?

A Yes. The Department of Health reckon it is well over 100,000 in England and Wales. We reckon it could be anywhere up to 400,000. Clearly, whatever the figure, 8,000 a year is not making any in-roads into that. Just in contrast, France has identified 60 per cent of its prevalent pool; Australia 90 per cent. We are talking 10 to 20 per cent.

MS WILLETS: What methodologies have they used in order to be that much more successful, or is it just simply an easier job for them because of numbers? It strikes me that if Australia is so successful, why we are not perhaps replicating some of what they are doing? I just wondered if you had a view on that?

A Part of it is actually case finding, actually looking for people, and we have not done that here. In France, by contrast, they have not yet done case finding -- that is something they are going to do now, because they have rather stalled at 60 per cent. They used very high profile public awareness campaigns.

THE CHAIRMAN: Would case finding mean asking general practitioners to notify the authorities, that sort of thing?

A Asking patients about any of their risk factors and then offering them a test.

THE CHAIRMAN: I see.

A Proactively looking. I mean, perhaps I will come on to that now, if you like. We asked for case finding to be part of the Quality Outcomes Framework for GPs, for the new GP contract for Hepatitis C, which seems like an obvious thing to do. We did not even make it past the first hurdle in this. So although that is an independent assessment at the first level, I still wonder why. It seems such an obvious thing to do. You know, it is particularly the case when some new research from the Trent Group -- which is a group of researchers and commissions around the Nottingham area -- has shown that the cost effectiveness of Hepatitis C treatment is extremely good in comparison to other diseases. In fact, for genotypes 2 and 3, the cost per quality of life per year saved is negative. In other words it saves money. Now, you simply don't get treatments, by and large, on the NHS that actually save money. So there seems to be very good NHS reasons why case finding makes sense. But there is just a lack of commitment to do things about Hepatitis C, in my view.

One of the things I would like to touch on here is that the Department of Health's awareness campaign,

called "Face It" has not helped at all with stigma. Hepatitis C is a stigmatised disease because of its association with drug use. One strapline that the "Face It" campaign used was "Face your past", as in, "You have done something you should not have done, now stand up and admit to it", which is absolutely outrageous and they have agreed to drop it. But this was typical in that they went ahead and did this without any consultation whatsoever. That is one of the reasons, in my view, that the campaign has simply not worked. They did not actually ask anyone with Hepatitis C.

MS WILLETS: But that sort of thing is more likely to discourage people from coming forward, surely. It would have a negative effect.

A Well, actually the numbers diagnosed in 2004 were 8,000. In 2006 they were 7,500. So you could say yes, indeed, that is having that effect.

They have also continuously linked transmission to sex. Now, sexual transmission of Hepatitis C is, in fact, very rare. All the evidence says that. There was a very good prospective ten-year study in Europe of 750 couples in monogamous relationships, and there was one partner in each case infected with Hepatitis C, and there was no transmission between couples, over ten years. Now it happens, and it is likely because there

is blood involved at some level, but it is not what you would call a sexually transmitted infection.

This actually, in our experience, is very stigmatising for people with Hepatitis C to think they have something which is sexually transmitted. It is a particular concern for people who are diagnosed a long time after infection, which is typically the transfusion recipients. One of their immediate thoughts is, "My God, do I have to go back and tell all my sexual contacts to get tested?" over what could be a 30 year period.

Stigma makes it very difficult to live with this disease, and some of the worst stigma that we have encountered is in the NHS. If you say you have Hepatitis C you are assumed to be a drug user and therefore a difficult patient. There are a lot of difficult preconceptions there.

THE CHAIRMAN: There is something I would like to clarify. How is it transmitted normally? Because we have had evidence of people who discover that their knives and forks had to be kept in a separate drawer in the house and that sort of thing.

MS WILLETS: That was at a time when less was known about the disease. That was the ignorant stage.

A It is blood to blood. It is a blood borne virus. Now,

to some degree it is actually quite difficult to get somebody else's blood into your blood stream where it can circulate, go to the liver, and start replicating. But at the same time there are also a whole number of ways that it could happen. You could have a cut and somebody falls off their bike in the street, you go and help them and they bleed all over you; things that you do not necessarily think about. A needlestick injury for hospital workers, and obviously IV drug use is a phenomenally efficient way of doing it because you are putting something directly into your vein.

THE CHAIRMAN: But is there still, so far as you know, this feeling that if a member of your family suffers from this that you had better be careful not to use the same towels and so forth?

A Yes.

THE CHAIRMAN: That still exists?

A Yes. There is still a huge amount of ignorance about this. One of the things in particular is people think that kissing is a way, because Hepatitis C has been seen in saliva. But the fact you see it there does not mean it is transmittible. So yes, this is a huge area of confusion.

MS WILLETS: People get mixed up with the other types of Hepatitis.

A Exactly, because there is Hepatitis B and so on. So yes, basically it is blood to blood.

Talking of the stigma, the music business -- because of the amount of drug use that goes on in the music business, this is the most prevalent life-threatening disease in the music business. The number of people who have come forward to say that they are infected with it, well-known people, even though we know that there are lots of them, and we know some of them, do not want to talk about it and two people who have, have done it because they have had treatment and eradicated the virus from their system.

It was quite interesting when Anita Roddick announced that she had it. The number of people who said to her, "My God, you are brave doing this". So there is that perception of stigma, even though she got it through a blood transfusion. Also, very interestingly, we had a number of patients say to us afterwards, "It is much easier for me now to say I have it, since Anita Roddick has said she had it than it was before". So things are changing but it is a long haul.

Talking about the professional awareness and the problem with QOF and not doing case finding, it has been very poor. GP awareness is very low. Just to give you one anecdote about this; there was, the week after

Anita Roddick announced that she had it, an article that we placed in the Daily Mail, about, in fact, the girl I referred to whose father had been diagnosed in 2005 and died within three months, and it highlighted the risks from infected blood. Our helpline was inundated, by mostly women, a lot of them extremely angry that nobody had ever told them that they were at risk. 15 of them subsequently rang us back to say they had been for a test at their GP and been refused a test.

Now, the Department of Health guidelines are very clear that if you had a blood transfusion before September 1991, you should be offered a test. So the Department has failed to get this message across to GPs.

THE CHAIRMAN: Do you know what the reasons were why they were refused?

A They were considered not at risk.

THE CHAIRMAN: They were not at risk, therefore you don't spend money on it?

A That was the reason given. One hopes that it was that rather than some kind of financial considerations, but the reasons given were that they were not at risk.

The Chief Medical Officer has accepted that not enough is being done to raise awareness, and has, I understand, committed to raising the tempo. He has said he will in a letter, so we hope that things will change,

because we do desperately need to get these people who are infected through blood transfusions tested.

I would like to say something about the Skipton Fund. A lot has been said, and I have read the Haemophilia Society's submission, but I wanted to just make three quick points. One, it was an awful long time coming. Two, it came as a result of pressure from the haemophiliac community, particularly in Scotland. At the first meeting to discuss how it was going to work, the first consultation meeting, it was absolutely clear that no thought had been given at all to recipients of infected blood. As a result, no thought had been given to the fact that a lot of recipients of infected blood may not have records of that. Haemophiliacs have, by and large, very good records. They are in constant contact with medical care. If you had a blood transfusion in 1971, you are jolly lucky if the hospital is still standing.

When this was pointed out, what they said was: we would rather pay a few people who are not deserving, and who have actually, you know, lost the records and got it through some other way, than miss out one single person who was deserving. That has not actually been the experience of patients and they have been refused.

There have been a lot of appeals, and we don't feel

this is satisfactory, nor do we feel it is satisfactory that people are not allowed representation at the appeal.

THE CHAIRMAN: What --

A They are not allowed --

THE CHAIRMAN: Can you tell us a little bit about the process? We have not actually heard. Who decides in the first instance?

A There is a panel, a submission is made, and in the case of people who don't have records, it comes very much down to what your clinician thinks. If your clinician is not as forthright as he might be, in other words he does not say, "I am reasonably certain that this is the only way that this could have been contracted", if they say, "I think it probable", that is likely to be refused. A lot of clinicians don't realise that they need to be extremely forceful about this.

Then, if it is refused, there is an appeals process, where new evidence is asked for and it is submitted to a panel.

THE CHAIRMAN: Is this a panel appointed by the trustees' fund, or?

A By the Department of Health --

THE CHAIRMAN: I see.

A -- because it is not a charity.

MS WILLETS: No, it is part of the Department of Health.
A Yes. It is actually called the Skipton Fund because there is a bit of the Department that works in somewhere called Skipton House, and obviously they looked up and thought, "Oh, that will be a name we could use".
THE CHAIRMAN: My memory may very well be at fault -- it frequently is these days -- but we were told that it was administered by someone from the Haemophilia Society, is that right?
A No. When it comes to the amount on the Skipton Fund, and certainly the Haemophilia Society is going to present more evidence on this -- but I would just like to say that coming up with some largely out of the air average figure is not a particularly good way -- it may be a very easy way of doing it and keep down administrative costs, but it is absolutely not a fair way. It is perfectly clear that £20,000 or, at maximum, £45,000 does not compensate people for years and years of lost earnings and so on.

On the other hand, I do know people who were infected in 1989 or 1990 and had absolutely no symptoms, a perfectly normal life, did treatment, sailed through treatment, went clear, and frankly it had no impact on their lives. So I sort of feel that there may be one or two people who actually, in a way, have been overpaid,

while the vast majority had been underpaid.

THE CHAIRMAN: So you would recommend that it should be done in the same way as the Criminal Injuries Compensation Scheme, then, where actually someone looks at it and assesses the appropriate rate of compensation.

A Yes. Admittedly we have a problem here in that the Department so far denies any liability and consequently that it is compensation at all.

THE CHAIRMAN: That is true, of course, for criminal injuries compensation.

A Well, yes. But yes, I would.

Then, getting on to the services, the English action plan, which has been out for three years now, has no timetable, no targets and no money. Frankly, after about 18 months, we reckoned it was just not being implemented by the primary care trusts at all and two advocacy staff were working flat out trying to make sure that people got treatment when they needed it, got seen in a reasonable time by consultants, had a proper standard of care, and I think you have heard this morning from the chair of the All Party Parliamentary Hepatology Group, so he would have told you about the audit that we carried out for them and that clearly showed that services were not being put in place.

Part of the reason for that is that the action plan

was so vague that primary care trusts felt they could get away with largely ignoring it -- I mean, they are obviously pressured from budgets as well. But part of that is because it has not been explained to primary care trusts that actually this makes sense to tackle this disease now rather than leave it. As one consultant said to me, "I have two choices: I can treat the disease or I can treat the cirrhosis". One of which is very much more expensive.

In terms of things being done rather slowly, I just want to go back to transplants. There is this working group that was set up by Rosie Winterton to look at how to increase organ donation and that is moving at such a slow speed that I do not know when it is going to report or what is going to come out of it.

I would just like to summarise now. If you have noticed at all a theme running through what I have said about the government response to Hepatitis C, and particularly to those infected with NHS blood, that is because there is one, and the theme is, frankly, of slow and half-hearted responses to this clear tragedy: in the introduction of blood screening in 1991; in the look back; in the introduction of action plans across the four countries; in awareness raising efforts; in the creation of the Skipton Fund; in response to the lack of

organs for transplant; and in improving services.

Of course, the lack of a public inquiry is again symptomatic of the whole approach to this and I commend you for holding this inquiry and giving up so much of your time to do it, but really you should not have been put in this position of having to do it. So I would like to say thank you very much.

Really, the point I would like to get across is that whichever way the inquiry finds -- if it indeed finds anything about it -- about government blame or not in the infection of people with Hepatitis C and HIV and CJD, that the actions taken by government in response in terms of Hepatitis C have frankly been wholly inadequate and deserving of censure.

THE CHAIRMAN: Thank you. Our primary purpose, of course, is not necessarily to apportion blame, but as you say to provide some sort of guidance for the future. Thank you very much.

MS WILLETS: You have talked about a huge amount of ignorance among the wider medical profession. In terms of the lack of interest or commitment at government level, may that have something to do with the people who were advising those bodies? Where do you think this lack of oomph comes from, if I can put it like that?

A I do not think it comes from the medical profession.

The people on the Hepatitis advisory board I think are really good and some of them have really pushed for things to happen.

What they have always said to me, obviously privately, is, we are really worried about overtaxing services, that is our big fear. What I think that means, certainly in terms of awareness raising, is if we go out there and identify all these people they will come forward for treating. The PCTs will throw up their hands and say, "You are creating this demand, you have to give us the money to cope with it". That, I think, is the problem. I think there is quite definitely a budgetary fear in here.

MS WILLETS: Yes, you are creating more patients.

A Yes. I also think that in terms of priority it is low because it is a stigmatised disease and there is a feeling that these people are not going to get any sympathy from the Daily Mail voters, so it does not really matter, which is just outrageous. Part of my job is to try and change that.

THE CHAIRMAN: But generally: "You must not tell people what they are entitled to, they may come and ask for it".

A Yes.

MS WILLETS: Thank you, that was very clear.

THE CHAIRMAN: May we stay in touch in case any other

questions arise?

A Of course, please.

THE CHAIRMAN: Thank you.

(12.11 pm)

(The luncheon adjournment)

(1.15 pm)

DR BRIAN IDDON (called)

THE CHAIRMAN: Right, thank you very much for being so prompt. Did everyone manage to get something to eat? Good.

Dr Iddon, we are very grateful to you for coming. Thank you very much. I think the easiest way to do this would be just to ask you to present your evidence and then we can ask any questions which arise as we go through?

A Thank you very much, Lord Archer, and thank you very much for giving me the privilege to present what little I know about this subject. This is a political perspective obviously.

I do so wearing three hats really. First of all, I have a constituent who is actually here today, and who has been present at each of these inquiry days, David Fielding -- I will say more about him in a moment -- and really I was propelled into studying Hepatitis C partly as a result of that.

Secondly, as you know I am Vice Chairman of the All Party Hepatology Group, and it is in that guise that I am here, really, this afternoon. But I am also, thirdly, Chairman of the All Party Parliamentary Drugs Misuse Group. Both of those are all party groups.

David Fielding, as a constituent, came to see me in a very poor state, not long after I had been elected actually. He is, or was at that time, a haemophiliac, and he had contracted Hepatitis C as a result of receiving NHS blood transfusions. He was in a terrible state when I saw him. He was going very yellow because his liver was obviously failing, and eventually the disease attacked his liver to such an extent he had to be admitted to the Royal Infirmary in Manchester, and I have some pictures which David is rather keen for me to let you see, actually. (Handed).

THE CHAIRMAN: Thank you.

A David was actually on the point of death just prior to one Christmas -- and married his partner of about seven years' standing, they had had children together -- and really was preparing himself and his partner for what he believed was the inevitable, when, to my absolute astonishment a miracle happened, and Jimmy's Hospital in Leeds called him over from Manchester Royal Infirmary. They had found a liver that matched for transplant

purposes, and he was rushed over to Leeds, and fortunately at the very last moment had a liver transplant, and I am very pleased that David is with us this afternoon.

He has obviously described his own experiences to you in detail, so I am not going to go into that. But of all the people who have died, around 850 people I gather, there have been very few transplants, for the obvious reason that liver transplants are not ten a penny, and I wish there were more available. So about 50 people have received transplants, of which we have at least one in the room this afternoon.

After the transplant, I was also more astonished that David appears to have lost the Hepatitis C virus, which is obviously not always the case. The Hepatitis C virus is a very virulent virus and stays around in the body, and can attack a liver transplant as well, and it is a difficult thing to go through, as you have heard, I am sure.

However, a strong point that I would like to bring to your attention, Lord Archer, is that these people have received what I would call a double whammy. Not only have they received the Hepatitis or HIV virus through a NHS blood transfusion, because they are haemophiliac, but after they have contracted one of

these diseases, and I am speaking particularly about Hepatitis C, sir, this afternoon, it is very difficult to get treatment for this viral infection, and I want to say more about that shortly.

Now, I first became aware of the dangers that Hepatitis C presents to people to contract the virus through my interest in drugs misuse. As I said, I am Chairman of the Misuse of Drugs Group. And many injecting drug users, for obvious reasons, contract this virus by sharing paraphernalia, usually syringes. Indeed, when I first met David, and for a long time after his transplant, he was very reluctant, as most people are who contract Hepatitis C through blood transfusions, to speak about this to the general public, because of the stigma. And I want to stress this. This is a small band of people compared with the other band of people who contract Hepatitis C through drug injecting, and because of that this small band of people have always felt stigmatised if they admit to having Hepatitis C.

THE CHAIRMAN: I do not know whether you were here this morning, but we had some evidence on that this morning.

A Sadly, I was not, because I had a Select Committee this morning. So I congratulate people like David Fielding for their courage now on standing up and revealing the

suffering that they have obviously been through.

Some years later, consultants from outside persuaded us inside Parliament to form a Hepatology All Party Group, and that was launched in the presence of the late George Best and his wife Alexis, a few yards from where I am sitting at the moment. And it campaigns on various fronts, obviously for improved access to liver transplants, and on the diagnosis and treatment of Hepatitis C for example, among other things.

I now want to present some evidence about the disease Hepatitis C.

THE CHAIRMAN: Sorry to interrupt you again, did you say when the group was formed?

A I cannot remember the exact year but I put it about five years ago.

THE CHAIRMAN: About five years ago?

A Yes, and I am going now to present some evidence about the Hepatitis C disease, and I have made you available some what I call slides, and I hope those are available to the general public and others sitting behind me. So I am going to refer those slides now.

Hepatitis C is regarded by the consultants in the area as a public time bomb ready to go off at any time in the near future. And we can't stress this enough. A significant date is 1989, when the Hepatitis virus was

finally given the "C" designation. Before that, of course, it was non-A or non-B or both. It is a fairly recently identified virus; and I think that date, 1989, is significant in view of the fact that these people contracted the virus, in many cases, in most cases I guess, long before that date in actual fact through blood transfusions.

It is an incredibly resilient virus. I have met middle class people, teachers, lawyers, who have contracted the virus, admittedly through drug injecting in the silliness of their youth, and it has taken 10, 15 or 25 years to exhibit the symptoms. It can hang around. It is very, very difficult to kill the virus, even in dried blood it will survive outside the body for a long period of time. It also has a high mutation rate, which is one of the difficulties in treatment. And it is the biggest cause of chronic liver disease anywhere in the world in fact.

Haemophiliacs in the past who have received contaminated blood, I use the figure 2,000 to 3,000, but I understand that 3,500 is the figure that has been presented more recently to this inquiry, but that is about right; injecting drug users also, as I have mentioned, contract this disease as well as haemophiliacs; and anyone actually in contract with the

blood of those two groups can also contract the disease.

So people are walking around it, here in London, in every city of the world, in every town of the world, who are possibly carrying the Hepatitis C virus without knowing it, and every time their blood comes into contact with somebody else, they may -- not always -- transmit it. Of course, those people who drink heavily are even more at risk of damaging and losing their liver, for the obvious reasons; they are giving their liver a double blow.

We estimate up to half a million people could be infected in England and Wales alone, and throughout the world a vast 17 million people are likely to be affected, many of them travelling from one country to another -- and this is, as I have explained, a transmissible disease. But the good news is -- that is the bad news, but the good news is there is a cost-effective combination therapy available for Hepatitis C, Ribavirin and Alpha-Interferon given together can cure a majority of patients -- not all sadly, but a majority of patients are amenable to treatment.

The cost is in excess of about £8,000 per patient, but obviously if it saves a life, that is an trivial sum of money, really.

MR MEHAN: Sorry, do you know if that £8,000 figure is throughout a lifetime or just --

A That is a cost for a single treatment for a patient with Hep C to become non-positive with the virus.

But we have to consider that the cost of a liver transplant, even if you can get the liver to transplant -- a matched liver of course -- it is much, much greater. And as I have already emphasised there is a huge shortage of all organs and especially livers.

In March 2001 -- when I came to this place, we started to press for a Hepatitis C strategy. There was none in 1997 when this government came into power. The happy news is that in March 2001 the Department of Health commissioned a Hepatitis C strategy for England. That was a significant date. It released the strategy a year later -- I do not know why it took 12 months for the strategy to be released to the National Health Service -- and in July 2004, look at the difference, three years here from the strategy being written to the strategy plan, the Hepatitis C plan, being published. It took three years, and in all that time people like me were pressing the Department of Health to do something about this time bomb that is there ready to explode.

The Hepatology Group when it formed became very concerned at these delays, and in actual fact published

a report in March 2005 called the Hepatitis C scandal. Anecdotal evidence of delays in implementation of action plans were coming to us all the time. So in February 2006 --

THE CHAIRMAN: Can I interrupt again for a moment?

A Certainly.

THE CHAIRMAN: Have you had any reasons given by the department for the delay?

A No, we have never -- I personally don't know of any. Some other professionals in the field might know.

THE CHAIRMAN: No doubt we will ask them, but ...

A But I have never had a good explanation for the delays.

So in February 2006 the Hepatology Group decided to launch a survey, and that was with the help of the Hepatitis C Trust, and I just give a quote here:

"Chief executives of primary care trusts and NHS hospital trusts should be able to demonstrate that there are adequate services and partnerships at local level to enable models of best clinical practice to be followed as set out in the Hepatitis C strategy for England."

That is a DoH quote, and that is really what we were trying to find out: whether in fact this quote had penetrated through to the front line of the clinical services.

I summarised the results. I do not know whether you

have seen our survey, Lord Archer, but I have a spare copy to leave with you.

MR MEHAN: I think it has been sent to us.

THE CHAIRMAN: I think we were given that at quite an early stage, but I do not think at that stage we were ready to fit it into the general picture.

A Well, you are very welcome to have this copy if you want a spare copy (Handed).

As far as I know, it is the only survey -- it was the only survey, certainly at the time, trying to find out what was happening in the National Health Service.

Now, of primary care trusts, 191 out of 305 responded, that is a response rate of 63 per cent, but only eight per cent of those, 16 primary care trusts -- which is a very, very small number -- had actually implemented the plan effectively in our view, and the consultants who helped us to do this survey had a ten point scoring scheme, which is actually explained in the report in detail, and I will not bother to explain it today.

So these figures are based on that ten point scoring plan that the consultants provided for us. 107, that is 56 per cent, implemented the strategy to a degree, and quite a number, 36 per cent, had hardly thought about it at all. If you looked across the country there were

areas where the strategy was being dealt with effectively, and there were many other areas where it was not, so we have the old postcode lottery that we know so well in other areas of the National Health Service.

MS WILLETS: I think we were actually told earlier on that it was 16 per cent that had implemented the action plan effectively.

A Well, I would have to check it, but I will look in the report if I am wrong.

MR MEHAN: That would be 16 PCT out of the ones that responded?

A Yes, it is 16, that would be right.

THE CHAIRMAN: I follow that this is what this is?

A Yes. Now, of the hospital trusts, the picture was about the same, 107 of the 165 hospital trusts who actually responded -- that is a 65 per cent response rate -- 39 of 85 hospitals reported significant delays for treatment, waiting times varied from one week to a year, and I do not think it has improved since our survey was published, and strategic health authorities are actually failing in their oversight role in persuading the hospital and PCTs to actually implement the strategy that we have been pressing for to so long, and the consultants, to be fair to them, have been pressing even

harder for for so long.

So in conclusion, our report says that unless vastly more vigorous efforts were made at that time, particularly at local level by PCTs, encouraged, of course, by targets in a timetable set out nationally by the Department of Health, we predicted when this survey was published, not that long ago, that Hepatitis C will in the future become a crushing burden to the Health Service, and that we will look back and know that we could have prevented the time bomb exploding.

So what we need is greater effort on liver transplants for those patients who have reached that stage, but what is absolutely essential is for people to be encouraged to volunteer for diagnosis if they think themselves vulnerable. Now of course that includes all haemophiliac patients -- and I hope you have received evidence that all of those can get diagnosis for any viruses that they may have contracted as a result of those blood transfusions, because some of those people who contracted the viruses, particularly Hepatitis C, may still not be displaying them, although I would have expected most people to have displayed symptoms by now and to be properly diagnosed, but there may be a few even today that have not been diagnosed. That is certainly true in the other majority group of

Hepatitis C carriers, the injecting drug users. And all the time that people are not diagnosed and not undergoing treatment, there is the possibility that they are spreading this virus, and it is very virulent as I have already indicated.

So I think this is going to become -- the Hepatitis C virus is going to become a major problem in future for the National Health Service. I do not think there will be the livers available, and I predict that there will be an increasing number of deaths from the Hepatitis C virus, as it vigorously attacks the liver, causes the cirrhosis and puts the liver out of service, turning the patient into a jaundiced patient and then beginning to result in death as the ultimate conclusion.

Finally, aided by the Hepatitis C Trust again, the all party group, Lord Archer, has decided to conduct a follow-up survey. We need to keep the pressure up, and I have not heard any results of the second survey yet, I think it is still ongoing. I mean you have had Charles Gore in front of you, I think this very morning, and he may have told you where we have reached on that, and that is the extent of my evidence. But let me say in conclusion also that I am very pleased that Lord Morris has persuaded you and Judith Willets and the supporting team to carry out this inquiry. It is very

much needed. I am looking forward to your recommendations. I hope the Government will accept them. If they don't, then I am sure the pressure will continue for the Government to have a full public inquiry. Thank you very much.

THE CHAIRMAN: Well, thank you very much, Doctor. The question in my mind, so little still seems to be being done at the level of primary care trusts. Do you think that the problem is that the trusts are not interested themselves in it, or are the doctors themselves not picking up symptoms from their patients? I follow that the symptoms sometimes take a long time to appear, but is there a problem with general practitioners about this?

A Well, I can only speak as a politician of course, you would have to ask the medical people that question, but my perception is there is still a lot of ignorance about Hepatitis C out there in the general community, especially amongst the general public, but I think also in the medical profession. And of course it is rather a specialist area, Hepatitis C, you need specialist nurses for the treatment because the treatment is not an easy treatment, this double treatment that I have referred to. It does have -- it does debilitate the patients for a while, and so you need specialist nurses and, of

course, you need specialist consultants. If you look at hepatology in general in hospitals, it is not a well served service. You would probably have to go to a regional centre from your local hospital to meet a consultant who would be able to handle Hepatitis C, diagnose it properly and then hand over to a specialist nurse during these difficult early days of treatment. And I think there lies the problem, that not enough consultant hepatologists are available, and probably of the ones that are available, not enough are available for Hepatitis C patients, because of course they are doing other things as well.

THE CHAIRMAN: I can see that there may be delays because of insufficient consultants and so on once the process has started. I was just wondering where the problem was about triggering it. I can only speak from my own experience. These days we are asked to have tests for a whole variety of things. I must confess, unless my doctor actually says to me, "I think you ought to go and have a test for so and so", I never get around to it. Is that part of the problem?

A I think diagnostics is general is a complicated area which is developing rapidly, and as you know the Government are just about to set up independent clinical assessment centres, where diagnoses for a variety of

disease conditions hopefully will be available, hopefully also Hepatitis C, but I do not think there is enough publicity out in the public to encourage people who either know or guess that they have been vulnerable, maybe coming to ...

I mean prisoners, for example. It would be very easy to contract Hepatitis C in prison. As Chairman of the Misuse of Drugs Group, I have been very critical of the way that drug treatment is carried out, still today, in most of our prisons. It has got a lot better in the last five or six years, but injecting drug users are using some pretty primitive material to carry on injecting drugs in prisons, unbeknown to the people who are supposed to be caring for them. And of course it is not easy to get hold of a syringe, for example, and if they get hold of a syringe, it is shared. And this disease is not just transmitted through sharing syringes, it is other paraphernalia as well, toothbrushes for example. If two people, one with Hepatitis C, shared a toothbrush, it is quite likely that the other would get Hepatitis C, from bleeding gums, of course.

THE CHAIRMAN: Yes, I think we have heard that.

MS WILLETS: So is there any evidence of mothers passing Hepatitis C down to their children?

A I am afraid, Judith, I am not able to answer that question. I have not even thought about that previously, and I would not even like to guess.

MS WILLETS: No, it is only something that has come to my mind today. I wondered if we knew very much about it. Could I just ask you to comment a little bit further on one of your points here about these very special visits, the very specialist area in terms of the nurses being funded by the pharmaceutical industry?

A Yes, the pharmaceutical industry, I know not why, have funded quite a number of specialist nurses in this area, presumably because -- I do not know, I just guess this is pharmaceutical industry are preparing the treatment products Interferon and Ribavirin. I do not know enough about that area. The Hepatitis C Trust will give you more information on that.

MS WILLETS: Okay, thank you.

THE CHAIRMAN: It seems that there is still an element of "We don't want people poking their noses into the way we do things" is there not?

A Maybe, I do not know.

MR MEHAN: Just on a very technical point really, just as an acknowledgment, you say about David Fielding and NHS blood transfusions, you also acknowledge that the haemophiliac community who have been infected through

Factor VIII blood derivatives and the like, so you acknowledge it is not just blood transfusions?

A No, because those blood products came from the USA of course, and I think it is a well-known fact that prisoners in the USA, as a privilege granted in prisons, were asked to donate their blood which resulted in the natural Factor VIII, before the synthetic Factor VIII became available, and I think that is where much of the Hepatitis C that our haemophiliacs in this country received. And around 1975, and you had Lord Owen in front of you this morning, and you have no doubt taken evidence from him, we were trying to become blood independent.

THE CHAIRMAN: Self-sufficient?

A Yes, self-sufficient in blood supplies for our own people. But it did not happen when it should have happened, and sadly we were still importing blood. In fact, I think we may still be importing blood products today. I am not sure about that. Maybe you have received evidence.

THE CHAIRMAN: Yes, the evidence seems to be that we are.

A We are still very short of blood supplies. That is probably due to the fact that people are not readily coming forward to donate blood to make the blood products.

THE CHAIRMAN: Well, yes. Perhaps we had better not go into that now because we did do have some specific evidence on the various factors that gave rise to that problem.

We are most grateful, thank you very much, Dr Iddon.

A Thank you very much for listening. If you have seen the photographs, I would like to hand them back to David. (Handed).

Thank you very much for seeing them.

THE CHAIRMAN: Again, if something arises from evidence which we hear later, perhaps we may come back to you?

A Certainly.

THE CHAIRMAN: Thank you very much.

(1.41 pm)

MR KELLY DUDA (called)

A I also have some documents I would like to submit.

THE CHAIRMAN: Yes please. Thank you very much for coming, Mr Duda. I should explain that the DVD -- I am still lagging a little behind modern technology in these respects -- but it arrived -- it was not your fault, but it arrived late enough to ensure that by the time copies had been taken for us all, we had not had time to look at it properly. I have seen half of it. I do not think Miss Willets has seen any of it at the moment.

MR MEHAN: I have seen all of it.

THE CHAIRMAN: Vijay has seen all of it. So do not assume

that we are familiar with it.

A Thank you, okay, very well.

THE CHAIRMAN: Would you like to submit the documents now or afterwards?

A Sure. (Handed).

THE CHAIRMAN: They are not something we need to use to follow your evidence?

A No, I think that that is just going to back up some of the things I am saying, so that you have something -- a variety of different news articles and internal company documents, CDC reports, FDA and things of that nature.

THE CHAIRMAN: That is certainly useful.

A To give you something to think about after I am gone.

MR MEHAN: Also, Mr Duda, we would say thank you that you have come especially across from the United States for this inquiry. Just to say thank you for that.

THE CHAIRMAN: We are very grateful.

A First of all, I want to say thank you all for having me here. This is a very important thing that you are doing, so it is a honour for me to be here, to be able to testify. I believe it is important for British citizens, it is important for American citizens, I think it is important for everyone around the world, because what you are doing and what you are addressing, especially with this issue, you are vanguards on. This

has never been handled.

The issue of the use of US prison plasma in products used around the world has been unfortunately under-covered, or sometimes not covered at all. Obviously there are some people who know about this, but what they know about is very little beyond rumour and what they have heard.

THE CHAIRMAN: That is quite encouraging. Throughout the whole of this inquiry, I do not think we have up until now heard of anything where we are in advance of what they are doing elsewhere!

A It is a great opportunity, so run with it. This Inquiry has done some amazing things thus far. There are a number of important revolutions that have been brought to light, and hopefully there will be plenty to come.

As you know, my documentary, "Factor 8 - The Arkansas Prison Blood Scandal", has been viewed by tainted blood victims around the globe, from the US and as far away as Japan, but I want to make the point, that nowhere have I been greeted by the kind of anger and outrage than when I showed it to infected haemophiliacs here in the United Kingdom.

When I showed it to British haemophiliacs afterwards, they called on the National Health Department, the NHS, to investigate, and they went to

great lengths to demonstrate against former US President Bill Clinton, who is also the former governor of Arkansas when this was going on when he recently visited Glasgow and Manchester.

So there is plenty out there that is yet to be answered. So today I can certainly talk to you about the quality of this blood, but I also want to go beyond that and urge the inquiry to take some proactive means to attempt to quantify this problem. So I would like to first start out by saying that -- I mean you heard testimony today about the self-sufficiency issue, or the lack of self-sufficiency in the UK. Obviously that opened the door for high risk blood and blood products to come into Great Britain, dangerous blood products, and of course I do not think there is a greater example of the grievous mistakes than that were made in the collection of this raw blood plasma than US prisons.

So I mean, sure, there is that self-sufficiency issue, but I want to deal with the idea that perhaps British citizens were actually targeted. How dirty was this product that was coming into the UK? I mean, ie you can look at prison plasma, but in addition there was un-heat-treated anti-haemophiliac factor that was being produced by pharmaceuticals after they had a heat treatment process, and after they were selling heat treated

products to people around the world -- they continued to produce this un-heat-treated medication. I want to know whether that was being sent here.

It is quite interesting that British citizens were seroconverting quite late compared to US citizens. By 1983 most of the haemophiliac population had been infected, but obviously there are still people being infected in 1985 and 1986 with HIV here, why? Was the UK a dumping ground, not just for prison plasma but for this untreated product? So what I would encourage you all to do is begin examining the batch records, look at the lot numbers of the patients, of the haemophiliacs, go to the doctors, go to the Health Department, whatever you have to do to collect these numbers, and they will begin to quantify this problem. And if you do that you can really sink your teeth into really being able to see beyond the quality and go forward from there.

THE CHAIRMAN: Again, if I could interrupt you?

A Yes, and I can help you with those batch numbers, and I know the people in the US that can help you cross-reference that.

THE CHAIRMAN: That may be enormously helpful.

A Including friends of mine at the New York Times, and of course all the information I have.

THE CHAIRMAN: Thank you that may be helpful certainly.

A I have nine CDs worth of drug company memos.

THE CHAIRMAN: We have not up until now heard evidence of the licensing system in the USA. We know a little about the licensing system here now, but could you tell us something about the licensing system there?

A Well, I mean, these -- all plasma centres are supposed to be -- well they have to be FDA licensed. I do not know if I am the expert to explain, I can just tell you what I know.

I mean every centre has FDA approval, however, for instance, how vigorously they monitored these facilities seemed a bit lacking. When AIDS reared its ugly head in 1983 and 1984, consciously, in the public's mind, in the United States, interesting enough the FDA postponed the length of time which they would go to examine these plasma centres from one year to two years.

I do not know, I mean obviously FDA inspectors -- in the beginning I do not think there was any licensing. If I may give you some background and then try and answer your question.

THE CHAIRMAN: Yes indeed. Could I say this though: in this country the licensing system seems to chip in at the point where the product is being put on the market, after the blood has been collected, after it has been processed. Is that what happens in the US?

A I think with the FDA the licence is to distribute, so I do not think you even have to have a licence to collect the blood. But once you sell it you do. So does that mean that I can go down the block and collect blood from all kinds of people? It raises a lot of interesting questions. So I do not even know if it has to do with opening a facility as it is the actual distribution of the product.

But the biologic industry around the world began in the United States with these plasmapheresis programmes in US prisons. I mean the actual process of collecting plasma was created and started in US prisons with Cutter; so they were doing medical experimentation, the government and these pharmaceutical companies, in US prisons. So it was not a stretch for them to begin to collect plasma and try out their new process for doing so. And as you know plasma is then fractioned out into a variety of different blood products.

This began with a doctor by the name of Dr Austin R Stowell(?), and he was running this programme that Cutter was testing in Oklahoma, Arkansas and Alabama prisons. So the biologics industry was born at that time, in 1963. Most people are not aware that of that, that it started from US prisons. This is something that happened along the way. The problems surfaced as soon

as the programmes were put into place. The CDC and the National Institute of Health investigated a massive outbreak of viral Hepatitis in these prison plasma programmes and in the prisons in 1963 and then in 1968.

I interviewed a doctor, who was an epidemiologist for the CDC at the time, and I have a document that I have submitted that is actually the report from the CDC on the 1968 outbreaks. And I said to him, "There is a reference to the 1963 outbreak, but I see no report on it. Is there a reason why?" He said, "There wasn't one written." And I said, "Why was that?" And he said he feared that the head of the CDC at the time when -- he had told him specifically not to write the report. And I said, "Why was that?" And the only thing he could point to was pressure from the pharmaceutical companies.

Now there was also a New York Times article from 1969 in that packet which goes into what I am talking about, how there were massive Hepatitis outbreaks that infected hundreds of inmates, and an undetermined number of them died. They were also doing medical testing alongside this as well. And even though the Nuremberg Code was cited, and even though the CDC acknowledges this was not a population to be driving plasma from, that there were inherent dangers and these problems

occurred, what happened? They continued to allow it to go on.

Now in Alabama they shut down the plasma programme, and in Oklahoma they scaled it back. In Arkansas eventually they just got rid of Dr Stowell, because the state said, "You know what, he is making too much money at that, and we can make it ourselves". And when I interviewed the people, the officials at the prison system in my film, they told me that the plasma programme began in 1967. They made no mention of 1963, and 1963 to 1967 and 1968 is what I am telling you about. So did they think I would not be able to find that out? I do not know.

But it sets a precedent for corruption, for mistakes, and for knowledge of what was going on in these environments, yet they continued to do it. So an industry was born, and prison plasma programmes sprouted up all over the United States for a period of time. The view was that these were cheap and plentiful and pharmaceutical companies
they were involved in either the collection and/or the purchasing of this plasma and then making it into blood products that were sent all over the world.

I need to make the point also that in 1982, late 1982, the CDC -- well, the FDA, I should say, the

Federal Food and Drug Administration, advised the big four pharmaceutical companies, which were Alpha, Cutter, Baxter and Armour, to please stop making blood and plasma from high risk sources, including prisoners, but there was no law saying that this could not happen. It was referred to as a gentlemen's agreement.

Unfortunately when the blood companies said they stopped, versus when they actually did, they continued using this blood product well into 1983, and of course it had a shelf life of a couple of years. And then in addition to that, there were a variety of back doors into Europe and the UK through Montreal and Zurich. So this blood programme in Arkansas ran until 1993, 1994. If it was not being used in the United States, where was it going? So again, as to the quality of the products -- I mean I have been able to establish that British citizens used -- infected British citizens used blood products that were made from Arkansas prisoners. The question is how many of them?

THE CHAIRMAN: You have traced some of them through?

A Yes. Carol Grayson's husband, Peter Longstaff was one individual. And I was able to do that by the batch numbers. So I am a bit bound by what I do not have. So you are in a perfect position to be able to ask for these sorts of things. Like I said, if in fact --

I mean, was it just a matter of mistakes being made, or was there something more? Was it negligence or otherwise? But we don't know. And I think your ability -- especially when it comes also to this un-heat-treated product. I mean if you were receiving the un-heat-treated product, your patients were, would you not want to know that? And also when you collect those batch numbers, by date you will be able to see this. And I keep seeing references of the stuff coming into the UK and these late seroconversions.

So it is quite frightening to me because I would have that thought that tainted blood victims here would have paralleled in when they got their infections closely with what was going on in the United States, and it was later.

So an industry was born and throughout the 1970s more prisons opened plasma programmes as I mentioned. Early on it became quite clear to the drug companies that the prison population had a high level of Hepatitis infection, including non-A and non-B Hepatitis. And attempts to stop the plasma collections from Angola Prison, which was in Louisiana, were met with strong resistance at Baxter-Highland, despite the fact that one of their own key scientists, and co-inventor of Baxter's anti-haemophiliac factor,

warned the company about the health threat. He had done tests looking at the liver enzyme levels of inmates there, and it seemed that it was raised. This was, I believe, 1972. And when he went to Baxter about this, he was fired two weeks later.

So interestingly enough, it is always looking back to see what we knew when, right, but this environment where they began the programme was also a perfect environment to see how it played out. The MP that was here before was talking about the high rate of Hepatitis C in prisons, so where else would you find it?

To me, that is really, really important. You have one of the major four pharmaceutical companies being warned by one of their big providers of blood plasma that there is a threat of non-A non-B here. And they knew it attacked the liver, and they knew it attacked the liver in different ways than he did.

Then also one former top executive at Alpha Therapeutics, admitted to me that the blood industry could have virally deactivated anti-haemophiliac products during this period, in the 70s, but chose not to because of the lower yields and higher costs associated, and instead wrote off haemophiliacs as already having Hepatitis B. And despite the known health risks "must be immune", and

they said if they were not immune, then they would surely die from this. So I was a bit confused by the rationale.

Obviously there were always risks being weighed, but if they are weighing the risks then they knew that they were risks.

THE CHAIRMAN: So the outcome, it seems to me, if they need this product, then they are probably haemophiliacs anyway, because they are the ones who need it. And if they are, then there is -- the chances are they already have Hepatitis B. Is that what he said?

A Yes, they wrote them off as already having Hepatitis B. And then if you don't buy that argument, it is justified, "Well, which is worse, dying sooner or later?"

MS WILLETS: Either way their view was it was too late.

A Either way you are having the president of a huge company, pharmaceutical company, saying, "We could virally deactivate this product", and chose not to. That is outrageous.

Prison programmes existed at one time or another in Alabama, Missouri, Mississippi, Louisiana, Florida, Tennessee, Arizona, Nevada, and Chicago's Cook County Jail. However, most of the programmes disappeared with the advent of AIDS. They knew about the threat long

before HIV because of viral Hepatitis. And they knew -- they began to know that they knew that there was a correlation between Hep B and Hep C and also with HIV. And before they had an adequate test for HIV, they looked at Hep B tests, surface antigen tests, antibody tests. If you had Hep B -- if you had anything, if you were positive, we were not supposed to take your blood.

The Arkansas prison system was one of the worst places to open up such an operation. Ruled unconstitutional in 1969 it was run more like a concentration camp, where medical care was virtually non-existent, the prison system would remain unconstitutional for 13 more years. The federal courts ruled that the Arkansas penitentiary system was unconstitutional from 1969 all the way to 1982/3, well into Governor Bill Clinton's second term. This is this is not ancient history.

I must point out also that they had black shoeshine boys and house boys servicing the prison wardens and the officials there, as well as leasing prisoners out on private land -- which is illegal -- a form of indentured servitude. Our constitution protects people, has amendments against this form of slavery, if you will, at the same time that it was running a plasma programme, while Bill Clinton was running for president in 1992.

So you step forward into the 90s and there is still backwards horrible things going on, and the blood was still being used and exported.

Another point, skipping ahead, that I want to make is that the Institute of Medicine in the United States recently issued a report recommending that pharmaceutical companies be able to go back into the prison environment to conduct medical and pharmaceutical testing on inmates.

To me this sets, again, a horrible precedent. We need to learn from what happened here. There is no informed consent, the CDC mentioned in Nuremberg Code at the time, this is just a bad, bad idea. And ironically they want to test Hepatitis and AIDS medications on the prisoners.

I mean, my fear is that the medical administrator for the Arkansas Department of Correction, his name John Bias, who I interviewed at length in my film, stated to me that if he could run the plasma programme today he would, and the only reason why it eventually shut down in 1994 was because they did not have a buyer.

So I can readily see, "Okay, now it is okay to bring drug companies into the prison environment to do medical and pharmaceutical testing. Well, now we will claim and state that blood is safe, because we had a heat treated

process. All right? So it is perfectly okay to go back into that environment." But I am saying, "No, it is not, because regulators and the drug companies need to learn from their mistakes, and there is always going to be new contaminants in the blood supply." I mean, could it be the CJD right now?

So -- with the Holocaust, the mantra was never again, never again, never again. Well. I am saying that now you are ripe for this to happen all over again, and because you are not self-sufficient, what have you learned? What do you know? How can you not make the same mistakes again?

THE CHAIRMAN: When you say you are not self-sufficient, you mean this country?

A Yes, the United Kingdom. If you are still receiving blood products, you know, I tried to present the analogy that if we regulated car safety the way we do blood, we would be in trouble.

Of course, the industry in the United States said, well, when there were lobbying groups to pressure them to use seat belts, it was, "We can't do that". And various other devices, what do you call -- air bags, "Oh, we can't do that either". But do we wait until people keep crashing and dying before we implement measures to make it more safe?

I do not believe the pharmaceutical industries have learned from their mistakes. It is a mind set and when you see the mind set persisting today, then weighing the risks -- I have to ask that question: are they just being stubborn? Because I do not want to be in a position in 2020 saying, "Well, in hindsight we did not know", and nobody is forcing them to.

As I mentioned about the medical care being virtually non-existent, the prison system would remain unconstitutional for 13 more years, until late 1982, and during this timeframe, as I mentioned, I was able to establish that Peter Longstaff, Carol Grayson's late husband, infected with AIDS and Hepatitis B and C, took blood products made from blood from Arkansas prisoners, and there are others here that I have been able to establish as well.

THE CHAIRMAN: When you say unconstitutional, by the way, do you mean because of the way the administration was run? That is with prisons not having proper medical abstention and so forth?

A There were a variety of reasons why the federal courts ruled against it. Obviously healthcare was an issue, but overcrowding and just the conditions themselves. Actually I have Holt v Sarver and Holt v Sarver II. For anyone who is interested, the briefs are available on my

website. They are searchable and can be downloaded. But our justice called it a dark, cold and evil world at that time. It was just absolutely diabolical.

So when you look at the history of the Arkansas penitentiary system, it was completely self-supported, meaning no tax dollars went into it, it was run at a profit, and there were inmate trustee guards that ruled over other prisoners, prisoners with guns. If you were governor of the State of Arkansas and you wanted to visit Cummins Prison, you left your hand gun, if you carried one -- we like carrying our hand guns in the United States -- to a prisoner in the tower. So you can see how it was set up, it was rife for corruption and brutality, and that is exactly what they got.

The plasma programme began in 1963. It was ruled unconstitutional in the prison system in 1969. So this notion that it was there for the benefit of the inmates, when they were given $3 in script, so they could buy cola trees or cigarettes or Coca-Cola, at an inflated price mind you. Its commissary does not hold much water. And of course the state made its cut. I wish that they had paid prisoners for their labour, better than take their blood.

I mean, this also goes into greater issues about how we regulate prisons and how we treat people, and this

is ...

THE CHAIRMAN: But of course our mandate is fairly limited.

A Of course, and I am not going into it. But what I am saying is here is a situation where you cannot always forget problems and how you treat people, because when you are taking their blood, that's going into the outside world. So you or I or anyone else could be the recipients of that horrible situation there, thousands of miles away.

MS WILLETS: When did you start to research this originally?

A I began in 1997. I began shooting my film in late 1998.

MS WILLETS: May ask you what prompted your interest and what made you go down this path?

A At the time I was living in California, I had come back to Arkansas, and of course, there were lots of investigations going on in Arkansas, the Whitewater had -- and the independent council, Ken Starr turning over rocks. And people were very, very uncomfortable.

THE CHAIRMAN: I think it is one of the states that is best known to us and the news media over here.

A Unfortunately. And I kept hearing these stories about the "good old boy" system in Arkansas. When I left I was young, so I didn't know how things worked, and so I kept hearing stories from people who had credibility about things that disturbed me. And I just kind the

raised the conversation casually about things I had been hearing, and someone I knew who had worked in the prison system said, "Well, did you know that they were collecting blood from the prisons?" And that just immediately horrified me, the very thought that this was going on.

But then when I also understood a little bit about the history of the prison system, there was an film called Brubaker, starring Robert Redford, that was made in 1980, which was about the same prison system, so I knew about that. And then when I heard this was being used in the United States and exported, and that there were problems, and I also was told at the time there were kickbacks involved, and they did not know how far this went, then I became alarmed. And the more I looked into it the more I found, and the more it tentacled out; and at a certain point I realised I had a responsibility, a civic duty.

I still was not looking at that time at shooting anything, but I realised if I did not, it would go away, it would never be told. So just out of sheer thought for the greater good.

THE CHAIRMAN: Presumably these things were known in Arkansas back in the late 1970s and the 80s, were they?

A What things?

THE CHAIRMAN: The things you have been telling us about, what went on in the prisons.

A By whom in Arkansas? You are referring to the conditions of the prison system?

THE CHAIRMAN: Why I was asking this is -- again and again, and quite properly, we have run up against the comment, "Well, things were very different in those days, we didn't know all these things". Really the question I was asking was: was that widely known outside Arkansas?

A Probably -- well, again, that is an open question.

Q It is difficult to answer, I follow that.

A Well, are you saying did other people outside the state of Arkansas in the United States, were they aware of how the prison system was being run?

Q Yes. And how blood was being collected?

A Not your average American, no. Certainly the pharmaceutical companies that were taking prisoners' blood knew about it. Although at the time I must say there was a warden who was trying to reform the prison, and he eventually was able to oust Dr Stowell. Of course, as I mentioned, I read articles where they were saying he was making too much money -- they didn't stop the programme, they just decided they would cut the middle man out. The wardens had torture devices referred to as

a strap and the tucker telephone, which was used to attach to the testicles of inmates; and they would crank this old style phone and send electrical charges. So that stuff was well known; he was able to get rid of that. He was trying to get rid of the inmate trustee guards. It that only lasted a year when he began unearthing mass graves of prisoners, and so at that point it made world wide press about the conditions of the prison system, and there were people in 1969 reporting in Japan about the conditions there. But obviously they were not aware of what was going on with the blood plasma.

THE CHAIRMAN: The question which we may need to answer is: how widely known was this in this country, and if so when? And the answer seems to be that certainly in the 80s, it was not widely known in America.

A No. In late 1982, because of the increasing threat of HIV, the US Food and Drug Administration advised the four big pharmaceutical companies to stop using prison plasma in their blood products. As I mentioned, eventually the companies would stop, but not immediately. What was not still being used in the United States for manufacturing was dumped overseas to Canada, Europe and Asia. The door was not even wider open for places like the UK to the threat. It was known

that prisoners were ten times more likely to carry the HIV virus in the United States, and there was estimates of between 30 and 60 per cent Hepatitis infection in the prison system.

In late 1981, 1982 and 1983, federal regulators at the FDA discovered major problems at the Arkansas Department of Corrections plasma programme, eventually shutting it down and revoking its licence to operate in 1984. International recalls of tainted blood from the Arkansas Department of Corrections failed; they were not able to get this stuff back. I think what I was able to establish was that that recall, the conditions that existed, what was happening that led to this bad blood getting out was a day in the life of the programme. The cat was out of the bag.

Despite these problems the state government under Governor Bill Clinton managed to get the operation restarted six months later. So in the midst of AIDS hysteria, after they knew there were problems, after they knew there were international recalls, after they knew the licence had been revoked, what do they do? Everything in their power to get the programme back up and running again, with the same people, mind you, operating it.

The programme would continue to operate for another

decade, the last of its kind in the United States. The estate programme only shut down its doors for good in 1984 due to lack of a buyer.

Of course the president of Health Management Associates, which was one of the companies that managed the prison plasma programme for the state, was a man by the name of Leonard Dunn, and he was a political friend and ally of Governor Clinton's at the time. It might be interesting to see what the former president's knowledge and role was in this as well, and how he might be able to help answer some questions too on behalf of the inquiry, or the victims.

THE CHAIRMAN: Well, whether we can conduct an inquiry into that I am not sure.

A You can always ask. He is in the global AIDS initiative, he is quite visible and vocal about his attempts to rid the world of HIV and AIDS.

MS WILLETS: Is there anything else you want to add to what you have said there? What do you think needs to happen next?

A Like I said, I think it is imperative that an attempt be made to quantify this programme. I can continue to talk about the horrors of the quality of it, but I feel in order for this to have teeth, and it is a relatively simple process to do, is just to ask for these records.

So that we can begin to look at those lot numbers, not just for the prison plasma issue, but also when it comes to the issue of the un-heat-treated products that may have been sold and used here, which would explain a lot of things. I think that is really, really important.

MR MEHAN: Do you think it is important to satisfy the end recipient that they might know that their infection or infections might have come from the Arkansas prison blood collection and in fact there right? Because how can that be satisfying, they have got the infections now.

A No-one can undo what has happened. All you can do is help inform them as to how and why it happened, and then with that information hopefully shining light on it, it is there for the record so that things like this cannot happen again.

THE CHAIRMAN: Depending on what records still exist and whether they are traceable of course.

A And whether they have been shredded or not, which seems to not only go on in your country but in the United States and elsewhere. I have run into that a few times.

For 20 years the blood industry had known about the hazards associated with harvesting prisoners' blood, because product recipients had contracted Hepatitis and

other diseases. The link between Hepatitis B and AIDS was identified in 1983; most people with AIDS also had been infected with Hepatitis B. And by the time the pharmaceutical industry officially recognised the AIDS epidemic a year later, the damage had already been done.

And there was a Croner study that was backed by the drug companies. And according to that, 90 per cent of all haemophiliacs with AIDS in the US were infected by the end of 1983. I think that was very interesting that that was not the case here, and so, again, going back to these batch numbers, you might begin to answer some of those key questions, what was going on, where was it coming from, why so late? You know, the knowledge was there.

One of the problems -- you run into this in Canada and Australia, this whole notion of self-sufficiency. Obviously it is not an easy conundrum to solve, but I think, once again, as a part of that decision-making process, America was looked at as a gold standard. Not only did other countries need the product, but they also looked at the FDA as sort of being the be all and end all.

But at the same time they were a bit willy nilly sometimes in how they applied that. It was like: okay, well, we want to look past doing our own work we will

just look at the gold standard. And then when we don't agree with it, we will say, "Well, this is not the United States". So they were able to hide behind that, saying, "Well, if it is okay in America it will be okay here", just blindly going on about their business. And, of course, to satisfy that greater demand, the pharmaceutical companies went far and wide, as you already know. It wasn't just prisoners, it was skid row donors, there were border towns that were very high risk, and they also went to Africa.

THE CHAIRMAN: I was going to say, one of the problems that took -- was part of the debate here is that they in some cases they were going to the Third World, and taking plasma from countries which needed the plasma themselves.

A Yes, yes. Isn't that amazing? Then there was another thing that has been described to me especially. A lot of this at a certain point was being punted to Montreal. And Canada, for example, they were on a non-pay donor system, but had to give way to that because of a lack of supply, so obviously that opened them up to greater risk, that they were not allowed to use prisoner plasma in product there or blood as early as 1972.

A company called Continental Pharma is a huge importer and exporter of blood products all over the

world, and they were in a position to know that in Canada it was not deemed prudent to use this prisoners' plasma, but they had an FDA approved site in the United States, and they could take that blood, sell it to a Crown owned corporation, 47 per cent owned Crown corporation, and fractionate it out and kind of play in the middle. So it was called blood laundering to me by certain officials up there. There was also the question of the products being relabelled once they are processed, not knowing -- and how are you going to know unless you do a lot of digging -- where it comes from. And the end users, the haemophiliacs, certainly did not know. And they were never given informed consent. I was speaking to a gentleman earlier that had mild haemophilia, and I hear this over and over again, "I could have used cryoprecipitate if I had known how dirty this product was, and it could have saved my life". But they were never given those options.

I do not know how much was known here, especially by the doctors, but I have seen some documents when other doctors in the United States were warning people here, officials --

THE CHAIRMAN: Certainly we have seen some of those.

A -- where the stuff was coming from, so ... again, I can discuss ad nauseam about the quality. But now that you

know the quality and you have documents to support this, not just my film and my testimony, it is what you do with it. And again I think there is some outstanding questions left unanswered here that we can help you answer. So again I urge you to make that request.

THE CHAIRMAN: And I hope we can stay in touch.

A Absolutely, anything else that I might have that would be useful to you.

MS WILLETS: I just wondered -- sorry, we are running over time, but is your conclusion -- where would you put, in terms of your conclusion, on the scale of mismanagement and negligence, where do you think -- is this kind of a series of bungles, or is it about financial motivation, is it about a very poorly run system, what is your sense --

THE CHAIRMAN: You mean in America?

MS WILLETS: In the States, yes.

A I think it is all of the above. Again, sure there is bungling, because it is going to happen, but fool me once shame on you, fool me twice shame on me. I mean how do you bungle --

I don't mean to fixate on it, but when you look at the state of Arkansas, let us say they are ignorant of what happened in their own system in the 60s. Okay, well you are certainly not ignorant of it when it is

happening in the 80s. How in the world could you restart this programme? And why in the world would anyone want to continue to take this? Sure this is bungling, there is a lot of misinformation, there is a lot of things that people did not know; but my point is that there is a lot of information they did know. And they just continued to move on.

You know, I just want to say that, on that note, my investigation, when it came to the Arkansas prison system, uncovered a great deal of information relevant to the Longstaff case, and others here, demonstrating that US federal regulations were violated, allowing drug users, prostitutes and sick inmates to routinely donate in the prison plasma programmes. Blood companies claimed prison plasma was safe, even though they knew it was harmful:

"Despite 20 years of blood industry studies showing that prisoners were a high risk population for diseases, drug companies continued taking blood from inmates because it was cheap."

Factor concentrate products made from prison plasma were exported throughout Europe and the United Kingdom, I believe, and British officials some of them were aware of these risks. So I do not know if that goes to trying to help. I do not know all the answers.

THE CHAIRMAN: That is what we are trying to --
A Yes, but I have been able to cover a great many bits that would encourage more questions.
THE CHAIRMAN: It certainly helps to put that together with the other lessons we have had.
A Put some perspective --
THE CHAIRMAN: Yes.
A And I did not want to leave today by just saying, "Okay, this is what happened in the past, and was that not ugly", I wanted to be able to arm you, and urge you to be able to actually do something, be vanguards once more. You are a vanguard today by bringing me in. Be a vanguard by helping quantify this problem for the victims of this country.
THE CHAIRMAN: Well, that is why we are here and what we are trying to do, certainly. Vijay?
MR MEHAN: What is your view on why the United States has not yet had a public inquiry into their own supply?
A Do you know what the laugh is? Please note the large laugh from the audience.
MR MEHAN: Is it because they have just taken the legal route and been satisfied through that means, or they just don't feel that a public inquiry would unravel any truth that is not already in the public domain?
THE CHAIRMAN: Or is that a question which is difficult for

you to answer?

A I can only give you opinion, I can only speculate. There has never been a criminal investigation or any type of real federal investigation into how people were infected with AIDS and Hepatitis.

I think that the United States government's attitude was, "Yes, let's let this play out", if it does so, in the legal courts, once again leaving that responsibility and obligation to the very people who have died, or are dying to uncover this truth.

And then there was the Ricky Ray Relief Act and fund, that eventually was passed in the US Congress, in which some AIDS patients were allocated $100,000 each. So there is that notion of "Throw them some money and then we are done with it". I mean, there have been lobbying groups including the committee of 10,000 in the United States that have been trying to make happen what has happened elsewhere. I think, to be honest with you, that the pharmaceutical industry is just too powerful. We have 635 lobbyists, maybe more, in Washington. That is more congressmen than senators. You have at least one lobbyist per lawmaker in DC, whose job it is to get you to see it their way, so that is a enormous amount of power.

THE CHAIRMAN: In fairness, there is a genuine problem

I suppose. If they don't make any attempt at compensation, they would quite properly be criticised for that. But if they do, there is a temptation for someone to say they are trying to buy their way out of the problem?

A Absolutely, yes. They are to be commended for what they have done, but there is a lot that has not been done. And unless the pressure -- they are going to consider this old news. Hepatitis C, people need to realise that more people are going to die in this world from Hepatitis C than HIV, and yet it somehow is not as colourful as AIDS and it is truly the secret killer. And Hepatitis should not take a back seat to HIV in what happened here.

THE CHAIRMAN: Certainly, we have just heard about that earlier on.

A And who knows what else maybe percolating right now and in the future. Obviously I am trying to look forward with my fears, but just to be frank, hell, no, that would never happen in the US. It is just not going to happen. It will never happen and they don't care what happens elsewhere. There is that strong sense of it, "Well, if this stuff was dumped over there, you guys deal with it". Even by the US media.

Sure, if they see more and more going on elsewhere,

they will be encouraged to look at it more because they can't completely turn a blind eye. But I just think that is something where they think, "Let us just move on, the damage is done, let's move forward", so -- but there are still some attempts to try to get some type of federal investigation, especially, if nothing else, into the Hepatitis C issue too.

THE CHAIRMAN: Well, thank you very much, Mr Duda. That has been certainly thought provoking and stimulating. I think you have probably left us with a fair amount of work to do.

A Good, well, thank you so much.

THE CHAIRMAN: Thank you very much.

(2.30 pm)

THE CHAIRMAN: I may make the announcement that our next evidence session will be 25th July.

MR MEHAN: Not the 18th.

(2.30 pm)

(The evidence session concluded)