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(11.30 am)

LORD ARCHER OF SANDWELL: Shall we begin.

Good morning, thank you very much for coming.

PROFESSOR CHRISTOPHER BARTLETT (called)

We have your statement, Professor. Perhaps the simplest way to do it would be if you made the presentation to us.

PROFESSOR BARTLETT: I am very happy to.

LORD ARCHER OF SANDWELL: You won't object if we interrupt from time to time to clarify something.

PROFESSOR BARTLETT: No, not at all and perhaps I may elaborate a little as I go along. So first of all I'll deal with my statement, and then there is the letter from Dr Galbraith -- I think it is worth going over that -- and the short memorandum of evidence that he submitted to the Department of Health in 1983. So I will start with my statement, if I may.

So my statement -- I will just read it out verbatim, probably be helpful to be accurate. I wish to submit evidence on advice given by Dr NS Galbraith, who at that time was Director of the Communicable Disease Surveillance Centre, on advice given to the Department of Health and Social Security in 1983. The Communicable Disease Surveillance Centre was the centre responsible for the surveillance of communicable disease in England and Wales. It was part of the Public Health Laboratory Service and the staff were on National Health Service contracts, and Dr Galbraith was director.

I was a consultant epidemiologist to the CDSC at that time and I reported to Dr Galbraith.

The advice that Dr Galbraith gave, first of all, through a letter and then subsequently oral evidence at the subcommittee of the Committee for Safety of Medicines, and this section refers to the letter and a memorandum of evidence that was submitted.

So the advice was formulated on the basis of several events in early 1983, and a review of the scientific literature, including surveillance reports, particularly reports in the United States.

The Lancet issue of 30th April 1983 recorded a total of 11 cases of Acquired Immunodeficiency Syndrome in the USA in people with haemophilia. Three cases in Spain of AIDS in individuals with haemophilia were reported in the same issue.

Dr Galbraith contacted the health authorities in Spain and discovered that all three individuals had received Factor VIII concentrate manufactured in the USA. That latter part is not reported in the Lancet article.

LORD ARCHER OF SANDWELL: You discovered it --

PROFESSOR BARTLETT: By phoning them, yes.

LORD ARCHER OF SANDWELL: Just before you continue, we have just been discussing this -- I must confess we have had so many days from so many different sources that they are not totally clear at least in my mind. What I have been trying to do was to construct a timeline which I have not completed.

Was this is a surprise in 1983, really the first time people had stumbled across the problem?

PROFESSOR BARTLETT: It became, in association with AIDS, as I will call it, rather than the full title, it became evident in 1983 that there was a problem, in that cases of AIDS were being reported in haemophiliacs who didn't have the other risk factors that were being described for AIDS acquisition.

LORD ARCHER OF SANDWELL: I see. But hepatitis C as a possible condition --

PROFESSOR BARTLETT: Non-A non-B, at that time.

LORD ARCHER OF SANDWELL: It was earlier, was it? It surfaced --

PROFESSOR BARTLETT: No, it is when the diagnostic tests became available, and for hepatitis A and hepatitis B there were validated tests, and at that time it became clear there was another entity, hepatitis C, clearly in individuals with hepatitis who were negative for hepatitis A and hepatitis B. I can give you that date, actually, when it became available.

LORD ARCHER OF SANDWELL: That would be helpful.

PROFESSOR BARTLETT: I will make a note. I have a terrible memory.

It is very difficult to remember the sequence of events, actually reliably.

LORD ARCHER OF SANDWELL: If you are getting a number of different dates from different sources, yes.

PROFESSOR BARTLETT: May I continue?

LORD ARCHER OF SANDWELL: Yes please.

PROFESSOR BARTLETT: So I think I perhaps had got as far as reporting there were three cases in Spain who had received Factor VIII concentrate manufactured in the USA.

The same week CDSA reported a case of AIDS in a haemophiliac in Wales and inquiries discovered that that person had also used Factor VIII concentrate, so Dr Galbraith took a careful review of the scientific publications, including surveillance reports, and this lead him to propose to the DHSS a temporary withdrawal of all blood products imported from the United States of America that were made from blood donated after 1978, at least until the risk of transmission of AIDS became clarified.

His advice and the justification was set out in a short paper entitled "Action on AIDS", and that is the paper I will go through in shortly.

Dr Galbraith concluded that in essence the scientific evidence in early 1983 show that AIDS was probably due to an infectious agent, and I can go over the argumentation in detail, if that would be helpful, later.

An infectious agent, furthermore, with a long incubation period, possibly ranging from several months to four years. Only a small proportion of recipients of Factor VIII concentrate had developed AIDS, but by May 1983 the risk may not have been small. In view of the long incubation period and the fact that the earliest cases of AIDS reported in United States developed symptoms in 1978 and most reported cases had become ill in 1981, 1982 -- in other words there was a rapid increase in detection in the early 1980s and I can give you some detailed figures later.

I think this last piece of evidence about the risk was one where other experts at the time disagreed; they felt the risk was small.   So there was a different of opinion at that time and that came out in the meeting of the subcommittee of biologicals.

So Factor VIII concentrate from pooled blood donations in the USA in the early 1980s would appear to have an increasing risk of being contaminated with the AIDS agent. Many donors were known to be in groups with behaviours which surveillance data indicated placed them at increased risk of AIDS.

The particular risk factors I am referring to are those that use intravenous drugs and "homosexual men", as they were described in the report then, now more precisely described as "men who have sex with men", rather than that broader label.

It was known that -- I am sure it has been presented to you that the drug users donated blood for money and there was an overlap in the drug and gay cultures both in New York and California.

The mortality rate exceeded 50%. Some reports suggested 60%, and was expected to increase and the papers were suggesting an increase to 70% at a time. We know subsequently it was higher.

So Dr Galbraith sent his paper to the DHSS on 9th May 1983 and in the covering letter recommended that the early meeting be convened with haematologist, virologists and others, so that a decision could be made as soon as possible.

It is my understanding, actually, that the meeting of the subcommittee on biologicals was actually convened in response to Dr Galbraith's letter.

LORD ARCHER OF SANDWELL: I see, that was the trigger for it.

PROFESSOR BARTLETT: That was my understanding.

LORD ARCHER OF SANDWELL: We had heard that virology was pretty well in its infancy at that period.

PROFESSOR BARTLETT: You would have to ask a virologist. I am not sure you would agree with that, but certainly it has developed rapidly since then, like microbiology in general.

LORD ARCHER OF SANDWELL: Not that there wasn't anyone who knew all about virology, but that as a separate science it was developing. That is what we had heard.

PROFESSOR BARTLETT: I am sure your experts are better informed than I am.

DR NORMAN JONES: I think the distinction is between academic virology rather than clinical. Clinical virology was very thin on the ground at that time, although there was plenty academic virology.

PROFESSOR BARTLETT: So Dr Galbraith sent his paper to the DHSS on 9th May 1983, as I have mentioned, and he proposed an early meeting and we felt this was prudent in that we were not aware of feasibility of alternative treatment strategies, and we were not experts in the treatment of bleeding disorders.

I have been informed that a copy of the letter and the paper "Action on AIDS" have already been sent to your secretariat.

I should say I was not directly involved in preparing the documents, but Dr Galbraith sought my opinion on his final drafts and I have to say that I fully concurred with his conclusions and advice and was dismayed when the subcommittee concluded that the risk was small, because I, like Dr Galbraith, found the evidence was rather stronger than that, that it may not necessarily have been small at that time. We can go over the reasons for that in a moment.

LORD ARCHER OF SANDWELL: Yes.

PROFESSOR BARTLETT: That is my statement.

LORD ARCHER OF SANDWELL: Thank you very much, professor Bartlett. Would you like to turn now to the letter?

PROFESSOR BARTLETT: Yes, certainly.

Sir, this was actually addressed to Dr Ian Field who worked in the Department of Health and Social Security at that time:

"Last week whilst we were away in Geneva a case of the Acquired Immunodeficiency Syndrome in a haemophiliac in Cardiff who had received USA Factor VIII concentrate was reported. The case fits the recognised criteria for the diagnosis of AIDS. In the Lancet of the 30th April, three cases of haemophiliacs in Spain are reported. I have confirmed that had they received USA Factor VIII concentrate. In the same issue of the Lancet the tally of 11 reported cases of haemophiliacs in the USA is recorded and the paper describes the case in a multiply transfused child in the USA.

"I have reviewed the literature and come to the conclusion that all blood products from the blood donated in the USA after 1978 should be withdrawn from use until the risk of a transmission by these products had a been clarified.

"Appended is a paper in which I set out my reasons for making this proposal. Perhaps the subject could be discussed at an early meeting of haematologists, virologists and others concerned so the decision could be made as soon as possible. In conclusion, may I say that I am most surprised that the USA manufacturers of the implicated blood products have not informed their customers of the new hazard. I assume no official warning has been received in the United Kingdom."

I am not sure, in retrospect, that last part is accurate, because the disease control in Atlanta had published recommendations relating to donations of blood and the need to encourage individuals with certain risk factors to avoid donating blood, and I know --

LORD ARCHER OF SANDWELL: Published in a professional journal or something of that sort?

PROFESSOR BARTLETT: Indeed, and I have a copy of it here. There was March 1983.

DR NORMAN JONES: Can you give us the reference?

PROFESSOR BARTLETT: Yes, I can certainly give you the reference.

So this is -- MMWR is the name of the --

DR NORMAN JONES: So it was in a newsletter?

PROFESSOR BARTLETT: Yes, it's a surveillance bulletin. The morbidity and mortality weekly report of March 4th, 1983, volume 32, number 8.

DR NORMAN JONES: Thank you very much.

PROFESSOR BARTLETT: So -- and in fact it sets out, if I can just refresh my memory very carefully, that the National Haemophilia Foundation in the United States had made specification recommendations for management of patients with haemophilia and also they refer in the article that the statement on prevention of AIDS, control of AIDS, had been issued by the National Gay Task Force, the National Haemophilia Foundation, the American Red Cross and the American Association of Blood Banks and the Council of Community Blood Centres and the American Association of Physicians for Human Rights and others, it says.

MS JUDITH WILLETTS: Sorry, what were those recommendations?

PROFESSOR BARTLETT: Essentially, I think the main focus was to ask questions that identified individuals who might be at risk of AIDS and to ask them to decline donation, that was the main recommendation.

LORD ARCHER OF SANDWELL: They were -- please.

DR NORMAN JONES: On that point, I am afraid I don't know the answer to this, and I should, but at the time of those recommendations, had the five Hs appeared on the scene?

PROFESSOR BARTLETT: They were being recognised at that time. The early cases in patients -- that was the link with the African continent -- but certainly -- I am trying to remember what it was now, it is some time, homosexuals, individuals with haemophilia and so on, exactly, yes.

LORD ARCHER OF SANDWELL: But from what you said it appears at this time over there at least it was being assumed that doctors would inform their patients about what the proposed treatment and give them an opportunity to decline it.

PROFESSOR BARTLETT: I am not entirely clear. I don't -- I give you the references and I am sure it will be possible to secure the documents from the organisations I have mentioned, at least some of them, at this stage.

MS JUDITH WILLETTS: But the recommendations were specifically about discouraging donors?

PROFESSOR BARTLETT: That's right.

MS JUDITH WILLETTS: Rather than addressing the treatment of people with haemophilia who therefore may have been at risk from the products. So it's really concentrating on the donor side rather than the ongoing treatment of haemophiliacs.

PROFESSOR BARTLETT: It did talk about the management of AIDS but precisely what advice was given I really don't know; I have not been able to secure the documents.

MS JUDITH WILLETTS: Was there a response received from the letter to Dr Ian Field at the Department of Health?

PROFESSOR BARTLETT: We could not find it in the records at CDFC so there may not have been a response.

DR NORMAN JONES: I rather gathered from something you said earlier that probably the response took the form of convening that meeting.

MS JUDITH WILLETTS: On 13th July.

PROFESSOR BARTLETT: Yes.

DR NORMAN JONES: Nothing before that?

PROFESSOR BARTLETT: No, that I am aware of, that is. I should say, I wasn't directly working in the AIDS field or directly working in hepatitis A and B and other blood-born infections. I was an epidemiologist with particular responsible for investigating outbreaks and epidemics, assisting people at local level with more severe outbreaks and co-ordinating regional and national outbreaks, and I operated a training programme for public health doctors to train them in modern epidemiological methods for prevention and control of infectious disease.

DR NORMAN JONES: Could I ask you what Dr Galbraith's main professional discipline was? Was he an epidemiologist?

PROFESSOR BARTLETT: Yes, indeed, a public health doctor specialising in -- earlier he had a been a area medical officer in Newham in London.

MS JUDITH WILLETTS: Despite the possible warning, if it constitutes it in the MMWR publication with those recommendations, that does not itself address the two final points in his letter in terms of any warnings coming from the manufacturers.

PROFESSOR BARTLETT: You are right.

MS JUDITH WILLETTS: And any official warning, which is very different from something that may or may not appear in a newsletter --

PROFESSOR BARTLETT: Precisely.

MS JUDITH WILLETTS: -- which is not going to be read by an awful lot of people, I imagine. I don't know that --

PROFESSOR BARTLETT: I think that you are right. That is why I made the comment that I am not sure, in retrospect, of the accuracy of that. I have spoken to some American colleagues who feel there may have been information. Clearly haemophilia directors were informed; I would be surprised if manufacturers were not informed the Centre for Disease Control in Atlanta.

DR NORMAN JONES: I think it is worth just pointing out that the regular publications of the CDC in Atlanta carried great weight, they were very prestigious.

MS JUDITH WILLETTS: So would have been widely read?

LORD ARCHER OF SANDWELL: Among the medical profession.

DR NORMAN JONES: I think that is fair.

PROFESSOR BARTLETT: And scientists working in the field.

LORD ARCHER OF SANDWELL: But they wouldn't have been the Sunday reading for people who did different jobs.

PROFESSOR BARTLETT: So that was the letter. I really don't know if there was a formal warning to -- the final part, if I may -- to the United Kingdom. The fact that it had been published in MMWR means that the information was available to the United Kingdom, in a timely way, yes.

LORD ARCHER OF SANDWELL: Yes. Is it your view that it was read in the United Kingdom, among medical circles?

PROFESSOR BARTLETT: Would you say that again?

LORD ARCHER OF SANDWELL: The publication was read in the United Kingdom?

PROFESSOR BARTLETT: Yes, how widely at that time, it is difficult to say. Certainly as infectious disease epidemiologists we read it regularly and carefully.

Some laboratory directors did, I think, but it is true to say it probably wasn't widely read at that time, amongst other --

DR NORMAN JONES: Ordinary chaps --

PROFESSOR BARTLETT: -- working in the practice of medicine.

LORD ARCHER OF SANDWELL: There was probably a vast amount of reading.

PROFESSOR BARTLETT: Always, that is the difficulty.

MS JUDITH WILLETTS: I think the Dr Galbraith's point was something of a higher or more specific level perhaps would have been expected or required, rather than relying on UK medical professionals reading something in a publication. That is a very different way of gleaning information from receiving a letter that says, "We are really rather concerned about this and we think that it needs to be looked into". It is completely different. My inference is that he is probing slightly on that and he is asking a very important question, which is why I would be very interested to know whether he received an answer.

PROFESSOR BARTLETT: He cannot recall receiving a formal answer, we couldn't find one, and as Dr Jones has pointed out it was probably the meeting that addressed the issue.

LORD ARCHER OF SANDWELL: But the subcommittee had reported to the main committee, hadn't they, which endorsed what they said.

DR NORMAN JONES: So they must have met earlier.

PROFESSOR BARTLETT: The subcommittee met on 13th July and then the full committee met later.

LORD ARCHER OF SANDWELL: Presumably that would then become known to the Department; someone in the Department must read the minutes.

MS JUDITH WILLETTS: Someone from the Department was attending.

LORD ARCHER OF SANDWELL: Someone from the Department, of course, was there.

PROFESSOR BARTLETT: And the advisers within the Department working in that particular area would certainly have attended and set an agenda and so on.

Shall I go on to the memorandum?

LORD ARCHER OF SANDWELL: Yes, please.

PROFESSOR BARTLETT: Which is essentially justification for the advice. Again, he starts with, if I may -- it is called Action on Aids:

"The temporary withdrawal of all blood products imported from the United States of America made from blood donated after 1978 is proposed, and to the risk of transmission of Acquired Immunodeficiency Syndrome.

"Reasons for withdrawal of USA blood products:

"1. The AIDS epidemic in the USA is probably due to a transmissible agent."

Perhaps I can just elaborate on that later -- I think I will say, and I will pull out the points as I go along, it may be easier to do that way, I think the subcommittee on biologicals agreed it probably was an infectious agent, although there was some dissent. Some felt it may have been due to repeated stimulation with other agents, and I am not sure what evidence they put forward to justify that. But I think the meeting overall concluded it was probably an infectious agent:

"The agent is probably transmitted by blood and blood products. In the Lancet of 30th April 11 cases of AIDS in haemophiliacs ..."

Some of the terminology has changed over time, but I will just read it out verbatim, if I may:

"... in the USA, receiving Factor VIII concentrate, were reported. Three in Spain also receiving Factor VIII concentrate (I confirmed by telephoning Ministry of Health, Madrid), and a case in a child following multiple transfusions is described.

"One of the blood donors to this case developed AIDS seven months after receiving blood and died of the disease 10 months later.

"On 1st May the Mail on Sunday reported two cases in haemophiliacs in the UK. One of these ..."

I have multiply scanned documents, documents that have been scanned many times, presumably. This is right at the end of the scanning line, I think.

One of these, Professor Bloom's case, he is one of the expert advisers to the Department of Health attending the committees, I think, in Cardiff:

"... fits the accepted criteria of AIDS and had received USA Factor VIII concentrate. We have not yet been able to identify the other possible case referred to in the Mail On Sunday.

"Although the number of cases of AIDS associated with the administration of Factor VIII concentrate is very small in relation to the number of individuals receiving the product this may not indicate that the risk is small because in the earliest cases of AIDS reported in the USA developed symptoms in 1978."

Shall I just go over that again? It is rather an odd sentence.

LORD ARCHER OF SANDWELL: I must confess I was trying to grapple with it.

PROFESSOR BARTLETT: Partly the poor quality of the document I am referring to. He said here, and I think it is a very important point he made, actually, about the likelihood of risk:

> "Although the number of cases of AIDS associated with the administration of Factor VIII concentrate is very small (that is in relation to the number of individuals receiving the product), this may not indicate that the risk is small because the earliest cases of AIDS reported in the USA developed symptoms in 1978 and therefore USA blood products manufactured from donations before 1978 are very unlikely to have been contaminated."

DR NORMAN JONES: Can I just pause at that point?

PROFESSOR BARTLETT: Yes, certainly.

DR NORMAN JONES: I suppose that doesn't take into account the possibility that people who developed symptoms in 1978 might have already been infected and carried the virus for quite a long time.

PROFESSOR BARTLETT: Indeed, yes.

DR NORMAN JONES: But you have to start somewhere.

PROFESSOR BARTLETT: That is true, and there are later reports of individuals in France who lived in Africa and so on who fit the criteria of infection.

LORD ARCHER OF SANDWELL: Was it generally known there was a long incubation period?

PROFESSOR BARTLETT: By then it was known that it ranged from several months up to several years, possibly as long as four years. Yes, it was known, from the surveillance data.

Indeed, it goes on to say:

"The earliest reported case of onset of AIDS in a haemophiliac was in October 1980. Most reported cases of AIDS have been diagnosed in 1981 and 1982."

That reflects the rapid increases in the epidemic:

"In 1981 and the first six months of 1982 456 cases were reported, out of 506 since January 1979."

So most of them had been reported in the first six months of 1982, and -- sorry, this writing is not -- so in fact:

"In the first six months of 1981 there were 456 cases of a total of 506 cases reported so far."

That is just another way of saying the diagnosis was increasing rapidly at that time.

He does go on to say that 249 cases were reported in 1982.

He goes on to say:

"The incubation period is long, between several months and two years, and may be as long as four years.

Therefore one would not expect to see many cases due to USA blood products until a year or more after 1981/1982 donated blood products have been given."

LORD ARCHER OF SANDWELL: Yes, yes. So we have a timeframe.

PROFESSOR BARTLETT: When there will be individuals with the virus, with the infection, without manifestations of the syndrome.

"4. Factor VIII concentrate and pooled products would appear to have a high risk of being contaminated with AIDS agents because homosexuals and drug users are known to be frequent blood donors and each plasma pool from which it is manufactured is collected from as many as one thousand donors. Furthermore, it is possible that the AIDS agent may be present in blood of healthy persons for several months before onset of symptoms.

"5. There is apparently no known means of ensuring that blood or blood products are free of the AIDS agent. The blood given to a multiply transfused infant who developed AIDS had been irradiated before administration and that suggests the possibility of an agent resistant to the usual means of sterilisation.

"6. The mortality rate of AIDS exceeds 60% one year after diagnosis and is expected to reach 70%."

Each of the points I have made were carefully referenced and the list of references follows on from that. So I think it was a precise and cogent presentation of the evidence, scientific evidence, at that time. But I have to say that I'm not sure, and Dr Galbraith is unable to remember evidence that was presented by other experts, because there was uncertainty at that time, I have to say that, as to the etiology.

LORD ARCHER OF SANDWELL: So although there is quite a short minute about it in the subcommittee there would have been quite a long discussion, probably.

PROFESSOR BARTLETT: I think so, yes.

As for the infectious diseases epidemiologists, I think we felt fairly confident in the advice we set out there.

DR NORMAN JONES: Can I ask, if you can remember, what was Dr Galbraith's reaction to the opinion of the final conclusions and recommendations of the CSM meeting on 9th July?

PROFESSOR BARTLETT: I asked him that yesterday in a phone call to let him know I was giving evidence today. He said he was completely bowled over. I must say I was dismayed at the time. But I think it is important that I go on to make another couple of points, if I may, and one is that although the experts disagreed on the level of risk, the subcommittee did go on to carefully consider the treatment strategies, as I refer to them, and the meeting that Dr Galbraith attended on 13th July, it was accepted by the meeting that an infectious agent seemed likely. Some experts, as I mentioned already, put forward the view that AIDS might be due to repeated exposure or reactivation of known agents, particularly CMV and the Epstein Barr virus, and I am not sure what evidence they put forward to justify that.

But the majority of experts felt the risk was small. They suggested the benefits of blood clotting factor concentrates outweighed the risk of AIDS. That was their general conclusion:

"Furthermore, I gather the subcommittee considered withdrawing clotting factor concentrates and replaced them with cryoprecipitate. It was concluded this was not feasible on the grounds of supply."

There was another issue, actually, that impacts on that, and that is that I think clotting factor concentrates have consistently more Factor VIII activity than cryoprecipitate. The consistency has greater efficacy as manifested initially by the reduction in the mortality rate, and I think the life expectancy, I read somewhere, actually, was 25 years in individuals with haemophilia, prior to that, prior to the initiation of that treatment, the clotting factor treatment.

MS JUDITH WILLETTS: May I just ask, Professor Bartlett, would it be normal for -- when you are considering AIDS, would it be normal, though, for people to consider something that they had already identified potentially had a long incubation period as low risk?

PROFESSOR BARTLETT: I am not quite sure what their justification was, really.

MS JUDITH WILLETTS: Because as a lay person that strikes me as slightly strange. They have identified that this potentially has a long incubation period, they are talking up to several years; surely admitting that, and if that were the thinking at the time, would that not pose sufficient unknown factors in terms of risk?

PROFESSOR BARTLETT: Dr Jones has pointed out that they may not have read the surveillance reports that I referred to and that information on incubation period came about as a result of surveillance and studies of small clusters and indeed the case of (inaudible).

MS JUDITH WILLETTS: But Dr Galbraith specifically tries to draw their attention to that and he was clearly at that meeting, so one would have loved to have been a fly on the wall.

DR NORMAN JONES: He quotes, in his references in this report, a report from France in the Lancet in 1983, and it is quite a low page number, 200, in volume 1, so that would be very early in 1983.

PROFESSOR BARTLETT: Yes. Yes, he refers to that and I have a copy of that paper with me, a short paper.

MS JUDITH WILLETTS: In terms of other diseases with a long incubation period, would the consideration be that that would be potentially high risk or not?

PROFESSOR BARTLETT: In theory, because it indicates there may well be viable higher risk in the blood stream, with a long incubation period, yes.

MS JUDITH WILLETTS: For a long period of time. So would medical professionals not, therefore, consider such a disease potentially high risk? Sorry, I am not trying to put you on the spot, but I am trying to understand the thinking.

PROFESSOR BARTLETT: All I can say is that I certainly felt there was a risk and Dr Galbraith clearly had his own view on that matter also.

MS JUDITH WILLETTS: And a part of that was specifically because of the incubation period.

PROFESSOR BARTLETT: And that high risk groups were donating blood.

MS JUDITH WILLETTS: Which makes some of the conclusions slightly strange.

PROFESSOR BARTLETT: Presumably others who attended that meeting with opposing views will be giving evidence in due course.

DR NORMAN JONES: I suppose it is relevant to remember Dr Winter's description of the climate of opinion at that time, which was that the concentrate had issued in a new era of hope and positivity and therefore to start doing without it was a very big step.

LORD ARCHER OF SANDWELL: As they used to say, the wish was father to the thought.

PROFESSOR BARTLETT: Yes, yes.

Then, if I could just go over that final point, the subcommittee also considered withdrawing CF concentrates. I have made this point already -- no, I haven't made the point.

They also considered using USA concentrates manufactured from blood collected after 23rd March, when that particular advice was given. But they are not sure at that time whether adequate supplies would be secured. I think probably subsequently they were not secured. But those particular supplies with in high demand, presumably, and I presume the UK was unable to secure sufficient quantities of blood donated after that time for a while.

LORD ARCHER OF SANDWELL: Although we know the problem subsequently, and that is of self-sufficiency.

PROFESSOR BARTLETT: Yes.

LORD ARCHER OF SANDWELL: Was that ...

PROFESSOR BARTLETT: That is the conclusion of his statement, yes, yes.

LORD ARCHER OF SANDWELL: Thank you. That has been extremely helpful.

DR NORMAN JONES: That has been very helpful, thank you very much.

MS JUDITH WILLETTS: Were there discussions at the time of the heat treatment?

PROFESSOR BARTLETT: It is so difficult to know, and I have certainly looked at documents subsequently, but I think the view was that they could not be confident that heat treatment would be effective and it might also damage the level of activity. I think that was the view at that time. I think there were further discussions subsequently, I think quite heated decisions about it, but at that time, particularly as radiation had not been effective -- at some age you may have had some very unusual characteristics -- so I am not sure it was considered at that meeting, as such. I think the general view was that there was not an alternative method of treatment, either chemical or heat that they could rely on to remove the agent and sustain activity levels of Factor VIII.

MS JUDITH WILLETTS: Professor Bloom had written to the

Haemophilia Centre directors as early as January 1982, specifically referring to four commercial companies who were producing heat-treated product, because he goes on to talk about the need for studies conducted on people who had not previously received those products.

PROFESSOR BARTLETT: Yes.

MS JUDITH WILLETTS: So I am trying to get my timeline straight as well and I am having things here that are quite interesting discussions and possibilities as early as January 1998 that don't seem to be featuring in meetings that are taking place in July 1983.

PROFESSOR BARTLETT: If I may, chairman, I think you have the minutes of that meeting of biologicals and that can tell you whether or not this issue was considered in any detail.

MS JUDITH WILLETTS: We have that, thank you.

LORD ARCHER OF SANDWELL: I don't recollect a specific reference to that.

MS JUDITH WILLETTS: No, we have.

LORD ARCHER OF SANDWELL: Was there already at this time a debate about whether heat treatment might actually destroy the therapeutic effects?

PROFESSOR BARTLETT: Precisely, yes, the point I was trying to make, yes.

MR MEHAN: Could I just ask you to say a bit about why

Dr Galbraith is not here himself?

PROFESSOR BARTLETT: Yes, he has a rather severe illness, and is elderly now. He would very much have liked to have attended but is not able to travel now.

LORD ARCHER OF SANDWELL: Thank you very much indeed and we can remain in touch?

PROFESSOR BARTLETT: Yes, yes, certainly.

LORD ARCHER OF SANDWELL: This is when we adjourn.

MS JUDITH WILLETTS: It seems very strange to stop now. Shall we resume at 1 o'clock?

(12.07 pm)

(The luncheon adjournment)

(1.00 pm)

MR RODDY MORRISON and MR CHRIS JAMES (called)

LORD ARCHER OF SANDWELL: Thank you for coming back, Mr Morrison.

MR MORRISON: Thank you for having us.

LORD ARCHER OF SANDWELL: I think the best plan is to leave you to make your own presentations.

MR MORRISON: Yes, that will be great.

LORD ARCHER OF SANDWELL: We can generate discussion as it goes along.

MR MORRISON: Absolutely, and I think you have a copy of second submission, and I will summarise that in what

I say, and I am grateful for the opportunity to come back again and present the Society's second submission.

I am joined today by Chris James, who has recently joined us as the new chief executive of the Society, as well.

It is early days for Chris, so I will lead.

LORD ARCHER OF SANDWELL: Fine.

MR MORRISON: But if I just summarise first of all some of the points we made in our first submission, very quickly.

In the first submission we outlined seven crucial failures which contributed to the preventable disaster that has devastated our community and it remains clear to us that the Government failed to act on the clear warning signs and to take the necessary action to prevent infections being transmitted through the blood supply.

That it took over 10 years to ensure the availability of recombinant treatment in the UK shows that successive governments have failed to learn the importance of swift action where public health is at stake and it is therefore of the utmost importance that the lessons of the past are fully and demonstrably learned.

Our first submission also highlighted how these failures have affected families and communities; the injustice is palpable, that people who have been infected with life threatening diseases in circumstances that should have been prevented are living in poverty.

Our second submission looks forward and makes clear recommendations for an appropriate and inclusive formal framework for the ongoing provision of care. It also recommends a series of measures to lessen hardship among those infected by the contaminated blood disaster. The submission has been developed with our campaign group and I believe it to be representative of the wishes of the whole community.

If I could start with the provision of care. Traditionally in discussions about issues that affect them vitally, they have not had the chance to make an informed choice about their treatment options. I think that has been a recurring theme throughout the inquiry here. They were not even informed that they were infected for many years after they had been diagnosed.

This situation cannot be allowed to continue. Formal participation by the Haemophilia Society, representing people with haemophilia and related bleeding disorders, should be agreed for all bodies that make substantive decisions relating to the care and treatment of haemophilia. This will give people with haemophilia real influence in decision-making that affects their lives.

In order to ensure that the views of haemophilia community are represented in decisions about their when they are being made a formal national haemophilia committee should be created on a statutory basis. This committee would ensure that the national standards specification -- again we have provided a copy of that -- is given statutory weight, and would oversee an annual audit to see that the standards described are met and maintained specifically by representatives from the Department of Health, the UKHCDO, the Haemophilia Nurses Association and the Haemophilia Society.

In many ways, it would put the good work of the statutory alliance on a statutory basis and it should be noted that national haemophilia councils have been established on a statutory basis in the Republic of Ireland and Georgia and are working well.

The Haemophilia Society should also be entitled to formal meetings with the Minister for Public Health every six months at least. A similar provision should be made for meetings with relevant ministers of the Welsh --

LORD ARCHER OF SANDWELL: Just asking that for a monopoly, do you think there would be sufficient for an agenda for a meeting? You can have some sympathy for ministers -- I suppose I have an interest, having been one -- you have some sympathy with ministers who have pretty full diaries and they are asked to meet an organisation, and then the agenda turns out to be a little thin; would you settle for a Minister of State, or something of that sort?

MR MORRISON: I think the details of that could be worked out, but given the particular gravity --

LORD ARCHER OF SANDWELL: Do you think there should be six-monthly meetings?

MR MORRISON: I believe so, yes. Certainly to start with. I think the nature of such things is that if the agendas look thin, I am sure there could be some flexibility in that. If it was set up on the basis of starting like that, with agreement from all parties, they could be changed as required.

LORD ARCHER OF SANDWELL: Sorry, I interrupted you.

MR MORRISON: No, that is great.

People with haemophilia have also suffered the tragic results of the Government's reluctance to invest in the safest treatments and there must now be funds to fund the best available care. After all, we are the fifth richest economy in the world and if it can be achieved elsewhere, why not here?

LORD ARCHER OF SANDWELL: Perhaps someone can explain this. NICE, isn't it, who advise the NHS on what treatment should be available but does it take into account the cost of those treatments? How would that fit into your scheme?

MR MORRISON: I think it would be to take the recommendations from the National Haemophilia Committee.

LORD ARCHER OF SANDWELL: Before that.

MR MORRISON: The situation that we are trying to avoid is where the UKHCDO declared that heat treatment was by far the best and safest treatment available, yet it took 10 years from that announcement to fund the treatment, so we want to get a situation where there is a requirement that the recommendations are statutory, so we don't need to spend 10 years of campaigning effort again to achieve something that has been clearly recommended.

LORD ARCHER OF SANDWELL: Yes.

MR MORRISON: I think that effectively covers the next point, actually, but more effective treatments for HIV and hepatitis C should be introduced without delay following licensing also, and the same must apply to variant CJD treatments, if developed and required.

If I touch on the tendering process as well, in order to assist in the development of an open and effective (inaudible) and guard against unacceptable cost cutting, the Haemophilia Society should be afforded a formal role in the tender process. Haemophilia societies in countries as diverse as Ireland, Canada, Australia, Brazil, Uruguay, Georgia, Tunisia and the Lebanon are currently included in such a body.

The inquiry has heard many lay witnesses describe the healthcare difficulties that have arisen as a result of their infections. People with haemophilia who have contracted HIV and/or hepatitis C through contaminated NHS blood and blood products should not have to bear the burden of paying their healthcare. They should never be denied treatment or have their treatment delayed because of exposure to viruses and prions. In further recognition of the source of their afflictions, access to healthcare and assistance should be provided free of charge and on an prioritised basis to all persons with haemophilia infected with HIV and/or hepatitis C, and their dependants and spouses. This is the case in the Republic of Ireland, under the provisions of the Irish Health Amendment Act of 1996, and nothing less should be tolerated in the UK.

Specifically, people at risk of developing variant CJD must be guaranteed full access to all medical treatment, including dentistry and endoscopy. NHS

Trusts and dental practices must be guaranteed refunds for the cost of equipment that can only be used on one patient because of the vCJD transmission risk. Equipment must not be reserved for, and used on, multiple 'at risk' patients. People with haemophilia should be entitled to individual assessments of their vCJD status.

The inquiry has also heard that many people have heard they were tested for viruses without their consent and informed of the results for some years afterwards.

LORD ARCHER OF SANDWELL: Just before we pass on from the last point, we were having a discussion over lunch in fact about the post code lottery. Has the Society any views on this? On the one side of the argument you say well, regional autonomy is a good thing, a local regional authority knows what is best for the region and is in touch with everybody and shouldn't they be allowed to choose. On the other hand, in that case different regions will give different reports and, as we were saying earlier, probably an area which can't muster a strong muscular campaign will suffer.

MR MORRISON: Yes.

LORD ARCHER OF SANDWELL: What would be the view of the Society on that? Would you be in favour of emphasising the local freedom or having national standards which will bind them?

MR MORRISON: It would always be national standards. That is one of the main reasons to avoid that post code lottery, that there would be a national committee, and we would have a nationwide audit process to ensure it is applied nationally as well, so any places where it is not happening can be investigated and explored. But I think it is very difficult to apply an appropriate standard of care if there is not national standard. I think regional applies itself very well to certain things, but not to a national standard about the care of people with haemophilia and other blood disorders.

LORD ARCHER OF SANDWELL: Yes.

MR MORRISON: If I can turn to the testing for viruses, as well. Some of our communities suspect that their blood samples were used for research without consent. There are also concerns that some victims of the contaminated blood disaster have never been traced and actually have no idea that they are infected with the disease.

The inquiry has heard of the financial hardship that people with haemophilia faced as a result of the transfusion of viruses and the impact on their family, friends and carers. The Government must conclude a financial settlement that will fully recognise their loss potential and its effect on their current living standards. It should be a full and final settlement which would replace all of the myriad of current arrangements. These payments must be independently adjudicated for each individual and should be paid directly. There should be no more trusts or funds and that is in no way a criticism of the individual trusts and funds; they were set up as they were set up, but that is not what we want going forward.

LORD ARCHER OF SANDWELL: So that the level of financial assistance which would be given would depend on need, and not --

MR MORRISON: I will come on to that more, if that is okay.

LORD ARCHER OF SANDWELL: Yes, carry on.

MR MORRISON: One of the key points here is that the people affected feel they have been denied control over their own futures. In order that they can begin to regain their independence, settlement levels should be based on recognised legal norms. A settlement should assess the losses and loss potential of individuals, bereaved relatives, dependants and those cleared of hepatitis C naturally.

Carers, many of whom have sacrificed their careers, should be assessed separately from their partners. The settlement should not be means tested or subject to taxation. It should not affect past, present of future state benefits and recipients must not be asked to sign a waiver denying a right to future claims.

The inquiry has heard that people with haemophilia and viruses find it virtually impossible to access insurance services. I make no apology for referencing the Republic of Ireland a lot today, but in the Republic of Ireland the Government now assist people living with haemophilia and viruses to obtain life insurance, mortgage protection insurance and travel insurance.

Those infected pay the standard premium for a healthy person of their age and the Government pays the additional premium. The Government here should offer assistance on this basis to make insurance and mortgages obtainable.

In general terms, the Haemophilia Society believes that the Irish settlement is model of good practice because it includes patient representation, participation in the process, free access to healthcare, provision for insurance, and a reasonable financial settlement.

LORD ARCHER OF SANDWELL: I think we are going to hear a little about that later on.

MR MORRISON: You are indeed. Full details are in our submission, and of course Brian O'Mahony is giving evidence later.

LORD ARCHER OF SANDWELL: Yes.

MR MORRISON: It is our hope that the inquiry will recommend that the British Government adopts a similar approach. It should be noted that the Irish settlement, in contradistinction to what Lord Warner has repeatedly told the House of Lords, was made without the acceptance of legal responsibility and I think this is a point we would like to clear up once and for all today.

LORD ARCHER OF SANDWELL: I think it probably is clear. Lord Warner, of course, in all innocence, was saying what was there in his brief, but whoever prepared the brief seems to have fallen a little short of care.

MR MORRISON: And it continues. I had a couple of questions I was going to ask at the end, but it is exactly on this point, because this argument has been repeated in a letter from Dawn Primarolo MP, the Minister of State of Public Health to one of our members, Harriet Bullock, who has actually given testimony to the inquiry, and that letter was dated 10th July this year, and that erroneous point is still being repeated by Government, and it is one of the things I want to ensure is that in whatever way that the inquiry can help to get this put straight.

LORD ARCHER OF SANDWELL: Yes, yes.

MR MORRISON: And make sure that both Houses are advised of the correct position, because the fact that the situation in Ireland was presented as being different through the acceptance of legal responsibility which is not the case has always been presented by the Government for a direct reason for not having the public inquiry here.

LORD ARCHER OF SANDWELL: I think whatever else we may or may not be able to do, we can try to sort that out.

DR NORMAN JONES: Can I just ask you again the date of that letter from Dawn Primarolo?

MR MORRISON: Yes, 10th July.

Thank you.

I think that is not -- I am missing pages, here we are, sorry about that.

One other point following on from those is that because it is clear this is greatest medical disaster visited on any community that we are aware of in the history of the UK, an apology to the haemophilia community from the Government would both be appropriate and much appreciated.

The Haemophilia Society has a crucial role to play in supporting the haemophilia community's participation in formal bodies that we have talked about and providing advice, advocacy and other services for those affected by contaminated blood and this can only be achieved if proper funding for the work of the Society is provided.

Treatment for both HIV and hepatitis C is complicated by the patient's existing haemophilia. In the case of co-infection, treatment becomes very complex. There is a continuing need for the Haemophilia Society to provide services for this group of people, but the Government is currently trying to cut the Society's funding to nil, and it has been cut before, as well.

DR NORMAN JONES: Could I ask, have any reasons been given for that? By the Government, I mean.

MR MORRISON: Two main reasons, in the communication we have had. Firstly that where the funding is drawn from -- section 64 funding -- is presented to us as not intended to be enduring funding on an ongoing basis, and there probably is, you know, some strength of argument behind that, but that is where the money comes from, rather than the money being required.

MS JUDITH WILLETTS: I thought that was being phased out anyway.

MR MORRISON: I am not sure about that. Maybe you know more about that, Chris?

The other one is that obviously that is not our only source of funding and this is also presented as an argument against ongoing --

LORD ARCHER OF SANDWELL: Not only --

MR MORRISON: The Society's only source of funding. So if you do look at our reports and accounts, we do manage to get funding from corporates, from trusts, from pharmaceuticals, but we have to spend a lot of time and energy and salary cost in obtaining that funding and in no way should it detract from the fact that the core needs that apply here, which is our Government funding.

LORD ARCHER OF SANDWELL: Where did this come from? Was it a letter from the Department to the Society?

MR MORRISON: Yes, yes it was.

MR MEHAN: Can I ask you, is it a source of conflict that you might be funded by pharmaceuticals, as you just said?

MR MORRISON: Yes, we have a very clear and published set of standards. For example, we will not accept funding for one pharmaceutical for a particular thing. We always try to get mixed funding. But yes, it is a cause of potential unease and difficulty.

MS JUDITH WILLETTS: Many societies are in the same position and also the same position as regards section 64 funding.

MR MORRISON: Yes, absolutely, and again, if we draw comparison with Ireland, the Irish Haemophilia Society draws 90% of its funding from the Irish Government, whereas ours would be reducing to nil under proposals at the moment.

What we have outlined in the second submission are two very clear points where we believe funding is required. The first is supporting these formal bodies and providing the advice and advocacy for this and we have attached some breakdown of why we have arrived at the figures we have arrived at, within submission.

MS JUDITH WILLETTS: I think the Society is almost being put in the same kind of ballpark as other charitable societies who are needing to raise money and be supportive of particular causes. You are all sort ever being lumped together and perhaps treated in the same way, rather than perhaps acknowledging the level of the medical disaster and the ongoing problem that perhaps the Haemophilia Society needs to be looked in a different way and funded therefore in a different way.

MR MORRISON: That is certainly our contention.

MS JUDITH WILLETTS: I understand that.

MR MORRISON: That is what we are trying to put forward in the second submission.

DR NORMAN JONES: Can I raise a tiny point of detail -- you are effectively on page 10 of your submission. The Government should provide "funding for two infectious workers" -- oh, it's "infections". I thought you were proposing something rather undesirable!

LORD ARCHER OF SANDWELL: No, I had to work that out.

MR MORRISON: That is exactly the point I was going to come onto. That is the second of the two things where we think it is a clear -- for dedicated funding, because it is very highly specialised and we do argue that there should be funding for two infections, to be based at the Society and also funding for specific events, projects and outreach area in this area.

If I give some of background to this as well, it might be helpful. In previous years the Society was able, largely as a result of funding we had, to provide dedicated workers in this area. Thankfully a lot of the younger members of the haemophilia community thankfully are not impacted by this, and we need to make sure we are providing services across the board for the whole community, so it is very, very difficult to ensure in effect what would be almost a majority of our available funds are provided for this, which is why we are arguing that there should be dedicated funding for it from the Government. If that was to leave us raising funds from the variety of sources that we have talked about before for all our other work but at least we know that would be safeguarded and would not have to stop if the fund raising efforts were unsuccessful.

And so in order to ensure that the lessens of the past are absorbed and not repeated it is crucial we have the resources to ensure the community's participation in formal bodies and representation in tender commissions. The type of activity here would include recruitment and training of patient representatives to serve on the national haemophilia committee and the tender committee and participation in the annual audits. It is a large piece of work to do that.

DR NORMAN JONES: Who would do that training?

MR MORRISON: The Society and experts the Society would identify, and we would work in conjunction with the Haemophilia Alliance as it stands currently and the UKHCDO in doing that. We would like to do it already, but we don't have the money.

MR JAMES: Actually included within our request for funding is a policy post that would cover that whole area of patient representation and also awareness of policy and getting involved in all the necessary committees.

LORD ARCHER OF SANDWELL: Yes, I am sorry to interrupt your thread but whilst we are on this subject there does seem to be some fragmention within the various bodies which are working in this field. Is there overlapping or -- could I ask, is there any rivalry, or everybody attends to their own particular concerns?

MR MORRISON: Which kind of bodies do you have in mind?

LORD ARCHER OF SANDWELL: The Haemophilia Alliance.

MR MEHAN: Tainted Blood, The Manor House Group, Carol Grayson has her own group.

MR MORRISON: Yes, there is a variety of different types of organisation within that. I think there are certainly different campaign groups.

LORD ARCHER OF SANDWELL: But each dealing with a different aspect of the matter.

MR MORRISON: I think that has arisen historically over the time, that with the long-running nature of the campaign, people have taken the tack that they think will best serve what they are trying to achieve. I think probably we are at a point now where the community is more cohesive than it has been for a very long time. We have a campaign group which everyone takes part in. It is one of huge sources of pride to myself that there was a press statement yesterday from nearly all the campaigning groups you mentioned that joined together in terms of saying, "This is what we as a community would like". I am sure we will continue to have debating points as we go forward but a number of years ago that certainly would not have been the case. You would have seen a much more fractured group.

LORD ARCHER OF SANDWELL: My own experience in the voluntary field generally, either there is this danger of falling over one another's feet, but everybody is reluctant to withdraw their particular objectives.

MR MORRISON: Indeed, and I think it is one of the things we have been trying very carefully to work towards, is to make sure what we put forward is cohesive -- doesn't differentiate unnecessarily between HIV and hepatitis C for example, and to make sure that the carers are represented as well as the people who have treated themselves. In terms of some of the other bodies you mentioned there as well, the alliance is something which I think both the medical profession and the patient group organisation are very proud of. It is a great example of working together and developing a national care specification.

What we are really keen to achieve, going forward, is that that is put on a statutory basis. In many ways this committee that we're proposing in effect would take the place of the alliance, but would be a statutory body, and I know from talking to a number of doctors, that is what we are keen to do off the back of this is make sure we are looking forward and working together cohesively. It is one of the great strengths in the haemophilia community of pharmaceutical companies doctors, families and patients working very well together. It struck me at one of the World Federation Congresses that someone from a pharmaceutical company who had worked in a different field before said that they found it incredible that here was a congress taking place with medical experts, the pharmaceuticals and patients, you know, on an equal standing, and whilst the medical community and the Haemophilia Society will not agree on all points, looking back we are all very keen to make sure we join and work together going forward and we are trying very hard to work with them to make sure we are all agreed in terms of the committee and its scope et cetera.

So if I just tie back the loops on the funding for the Society that we were covering as well. The case, covering that representation, plus covering the infections working, equates to a minimum required funding in the region of £300,000 per year, to fulfill that role of facilitating in participation and representation on formal bodies and advising and advocating for people with haemophilia and viruses and providing the services and support required that we have outline. As I have said, our submission contains the rationale behind that level of funding.

So in summary, our proposals would put in place a framework which we believe would prevent a large scale public health disaster such as that which has afflicted our community with contaminated blood from happening again in the future. It would also bring haemophilia care into the 21st century in terms of patient involvement.

The proposals also include clear provision to reduce hardship among those affected by the contaminated blood disaster. Nobody should have to suffer a lifetime of poverty and penury as a result of their medical treatment. It is quite an incredible situation that those of us who have been fortunate enough to avoid the worst impacts of this disaster feel guilty when you look at the dreadful situations that people find themselves in who have not been so lucky. The proposals in this submission provide a basis on which the medical profession, the Government and the haemophilia community can progress together and in partnership. We hope profoundly that the inquiry will accept these proposals and recommend to the Government when it reports in the autumn. Thank you.

LORD ARCHER OF SANDWELL: Thank you very much, Mr Morrison.

DR NORMAN JONES: Sorry to return first to a relatively small detail. It is, but it is not unimportant. Page 10 again and the now corrected "infections". I am just trying to think about those posts; have you given thought, for instance, to such things as where they would be recruited from, what their career structure would be, what the jobs would lead on to?

MR JAMES: Yes, most certainly. I think there are a number of people very skilled already working in these fields and we would be looking to these resource pools to recruit from and I think also we would look very carefully prior to recruitment as to the development of that post and actually would follow the very robust human resource policies and procedures we have in this Society already in terms of professional development.

MR MORRISON: It would need to be able to recruit people with that specialist and skill. We have to recruit quite generalistically at the moment.

LORD ARCHER OF SANDWELL: Absolutely, but you could create a profession.

MR MORRISON: Absolutely.

MS JUDITH WILLETTS: Could you very briefly describe the process you went through to reach these conclusions and recommendations in terms of process, consulting with people, talking to the medical professionals, et cetera, looking to Irish model? Can you summarise that for me, because I think it might be helpful to have that on record.

MR MORRISON: Absolutely. Unfortunately, because of work commitments, I couldn't be at a lot of sessions but we have this campaign group, so there have been a series of meetings of that campaign group and a lot of people you have heard from at the inquiry take part in that, so drafts were produced, meetings held, just to discuss the points and make sure that people's own views were represented in terms of the submission going forward, so it has really been through that campaign group.

MS JUDITH WILLETTS: Which mostly would be representing patients, effectively?

MR MORRISON: The campaign group is kind of a conglomeration of campaigners in the field, so yes, it would be patients.

MS JUDITH WILLETTS: And family members, et cetera.

MR MORRISON: Whoever has history in campaigning on this, a very much an open invitation to all.

MS JUDITH WILLETTS: I was interested in the possible endorsement from the medical profession for these recommendations because I assume you have consulted with haemophilia doctors.

MR MORRISON: We are still in the process of consulting, we have some minor comments back at the moment and we will be taking that forward.

LORD ARCHER OF SANDWELL: But in principal they accept the idea?

MR MORRISON: In principal from previous discussions they accept the idea. I don't want to mislead and say, "Yes, in principle, they have signed up to everything that was in here", because we are just not through the process yet for time reasons, but --

MS JUDITH WILLETTS: Do we already have new rules for where it comes to testing the patients for the presence of diseases, viruses and such? I thought we did? I am sorry -- it is just a point of information, really. Because you are proposing that clearly we should have these, I thought we already did. Is that --

LORD ARCHER OF SANDWELL: I see some heads are nodding.

MS JUDITH WILLETTS: Perhaps we should just clarify with where we are on the current position on testing, then.

MR MORRISON: Clarifying that would be helpful.

LORD ARCHER OF SANDWELL: I am sure we can do that even later this afternoon.

MR MORRISON: Yes.

MS JUDITH WILLETTS: I should probably know the answer to this, but what is availability at the moment for people with haemophilia for recombinant treatment? Does everyone get it, or ...?

MR MORRISON: For people with haemophilia itself the commitment is that everyone who wants it can have it.

MS JUDITH WILLETTS: And that is the case.

MR MORRISON: I believe it is. We would be certainly taking huge interest in any cases where that is not the case.

MS JUDITH WILLETTS: I wasn't completely clear on this.

MR MORRISON: You will find instances of some people who prefer to remain not on recombinant --

MS JUDITH WILLETTS: But that is personal choice.

MR MORRISON: That should be personal choice.

MR MEHAN: Is it now a completely synthetic product and how come it has taken 10 years to roll out on a full basis?

MR MORRISON: Two separate questions, I guess. Why it took so long to roll out on a national basis -- one, was getting agreement to the funding for that treatment, because it is more expensive than the plasma concentrates, and that took years of campaigning effort before agreement from the Government to pay for that.

MR MEHAN: Were the Haemophilia Society involved in that campaign?

MR MORRISON: Absolutely, along with others. I think it's a case of any successful campaigning outcome is the result of everyone's efforts collectively -- they rarely happen from one party -- and that was achieved first in Scotland and Wales, and then in the UK as a whole.

I think the roll out of that was slower than we would have liked, clearly. It look longer. The point that causes anger and distress is the fact that to get agreement to the commitment to roll that out in the first place took so long, because in the mean time people were still being treated with suboptimal product.

In terms of it is it entirely synthetic, I will probably have to give sway on that one because there has been separate generations of recombinant treatment and I am by no way expert in this. The first and second generations I don't think would be classified as entirely synthetic. The third one takes it to another level, but probably until I've the detail there, I shouldn't comment much further. I am sure we can find out more answers than that.

LORD ARCHER OF SANDWELL: It may be that our recommendations can't be too detailed in respect of that kind.

MR MORRISON: I think that's where we would need the kind of collective we are talking about in that national committee making its recommendations.

LORD ARCHER OF SANDWELL: It would follow rather than precede --

MR MORRISON: Yes.

LORD ARCHER OF SANDWELL: -- the major agreement.

MR MORRISON: Indeed, indeed and there are people with strong views about the relative merits of the third generation compared with the second but there are also how many products of our generation's standard are available and I think that's for more qualified person than a lay person such as myself to make a call on. You could follow up with Brian O'Mahony as well.

LORD ARCHER OF SANDWELL: Yes, we can.

MS JUDITH WILLETTS: Do you have a view on why the roll-out was not given priority?

MR MORRISON: In terms of why it wasn't committed to in the first place, in terms of providing funding for the recombinant product across the board, I think it was purely a funding issue. In terms of why it took longer than ideal to roll out once that commitment had been made I am not quite sure. I could hypothesise, but ...

MS JUDITH WILLETTS: So could I.

DR NORMAN JONES: If I can, at the risk of oversimplification, if one was to look at your whole submission as having two main thrusts. One is financial/compensation/insurance etc issues, the other is patient participation and the creation of the National Haemophilia Committee.

MR MORRISON: Yes.

DR NORMAN JONES: Now, I have been trying while sitting here to put myself in the shoes of the secretary of state, which I find very uncomfortable and altogether rather embarrassing, but supposing this proposal was to go forward, how do you respond to a point of view that he might conceivably take, which could be summarised very simply as: well, if the haemophiliacs, why not the patient with kidney failure, why not every other patient group, everything down to the ME Society, for instance? Could we see here the thin end of a potentially enormous bureaucratic wedge. I am not saying I believe that, but I can see some.

MR MORRISON: It is a very, very interesting question and it is one we are always wary about commenting on too much because what we would never want to say is that our particular medical condition is the most important medical condition in the world, because it is just disrespectful. All we can say on that is that the particular circumstances which have impacted the haemophilia community so hard, when you look at the percentage of haemophiliacs who have been impacted by the contaminated blood disaster, it appears to us to be quite unique and on the basis that lessons clearly haven't been learned in the past, I think there is a very strong argument for a particular approach to haemophilia and haemophiliac patients because of that and therefore there is very particular circumstances that lead to the recommendation for this council.
I think if we hadn't had the affliction that we have had, we would probably be taken along quite happily

taking whatever treatment was prescribed and we would not be talking about it.

DR NORMAN JONES: I think you have an important point there. You also of course have a precedent across the Irish channel, and I suppose as an alternative to mass emigration to Ireland --

MR MORRISON: It is a very interesting point in terms of the post code lottery. I am a Scot who has lived in England for a long time. I came very close to moving back purely on a treatment basis, very close, and it has been a cause of great concern for Scottish people in the past, just using Scotland as an example, haemophiliac children coming to an English university, until that treatment was in place across the board.

DR NORMAN JONES: Yes, yes, thank you.

LORD ARCHER OF SANDWELL: Thank you very much --

MR MEHAN: One small question and that is: is there a current campaign regarding dependants and widows and family members, in respect of settlement, as you put it in your statement, to reverse, maybe, the decision that, those haemophiliacs who died prior to August 2003, their family dependants should be receiving some form of settlement?

MR MORRISON: We haven't focused on that individual point because we are building the case for an inclusive settlement which would replace everything that is in place which has got a lot of iniquity in it. We have made the point previously that that is incredibly iniquitous in its own right. For one widow whose husband died for one reason to be treated entirely differently -- I think this has come out very strongly in submissions made to the inquiry. What we have tried to do is to not focus on individual points that we believe are wrong with the current arrangement but put in place a cohesive arrangement that would include all of that going forward.

LORD ARCHER OF SANDWELL: Indeed.

MR MORRISON: I have a couple of questions I would like to ask.

LORD ARCHER OF SANDWELL: I have one I would like to ask you.

MR MORRISON: Good.

LORD ARCHER OF SANDWELL: On a rather different matter, which is something which has raised its head more than once during this inquiry. In May 1983, the question arose of what should be done about commercially produced American products, with all the disadvantages we know about, as against the danger of not having any treatment at all, and the Haemophilia Society, as people made the point more than once said: well, please don't cease to licence the American product.

There seemed to be some doubt, some of your members weren't even sure if that was the case, but I take it is the case and perhaps you can comment.

MR MORRISON: I will comment at a high level, and if I could take a commitment to come back with the full detail of information we have.

LORD ARCHER OF SANDWELL: By all means, yes.

MR MORRISON: I think we have slightly incomplete records. We were looking at this this morning, in terms of the papers we do have available.

I think the point is we weren't in the room with the full information was being presented that allowed the recommendations to be put forward so we in a general sense took the recommendations from the medical community and I think that is what we need to look at in terms of the information that was made available to us at the time.

I think another point that we would want to draw out from this as well is in the treatment decisions that were being made. How was the balance viewed between the risk of treatment and known risks associated with that treatment and the risks of non-treatment?

LORD ARCHER OF SANDWELL: Which must apply in more than one medical field, I imagine.

DR NORMAN JONES: Yes. That was a particularly acute example.

MR MORRISON: Indeed. I would think the position at the time is that treatment levels were being increased for people and that is an important factor within it as well. Certain haemophilia bleeding is life threatening. A lot of haemophilia bleeding isn't, and the choice isn't between, you know, high likelihood of imminent death from bleeding. Very often it would be a very sore elbow or sore knee, and I think that is one of the things we have to look at.

LORD ARCHER OF SANDWELL: You would have to distinguish between various categories of suffering.

DR NORMAN JONES: It is a matter of balancing risks. It is not the same balance if you have a very mild form of the condition as a life threatening.

MR MORRISON: Indeed.

MS JUDITH WILLETTS: If it is something presented regularly why have some people with very mild forms of haemophilia been given something that is potentially a higher risk product?

MR MORRISON: I think it is something worthy of a lot of consideration.

LORD ARCHER OF SANDWELL: The criticism would be the place where they got the balance. In the end, they got it in the wrong end.

MR MORRISON: There are a number of factors. On that particular case, yes. I think it is too easy to draw black and white between life threatening condition, therefore treat --

MR MEHAN: Do you know if there was a distinct time when the Haemophilia Society's view changed and tipped that balance when they then felt clearly these products were causing a problem --

MR MORRISON: I don't know. I think we would need to go away and look through the records we have.

LORD ARCHER OF SANDWELL: If you can let us know subsequently.

MR MORRISON: Absolutely.

MS JUDITH WILLETTS: 24 years ago the Society would be more likely to be guided by the current medical opinion than perhaps a Society would 24 years later, for example.

MR MORRISON: And it would certainly be far different to having a National Haemophilia Committee when you are sitting in a room together looking at that situation. I think if that could be the case in 1983, and there had been a national haemophilia committee where all the evidence of the day was on the table, then I think the Society could be held to account in the same way as anyone else. But when people come out of the room with the knowledge and give advice, then you are guided by your physicians.

LORD ARCHER OF SANDWELL: It was a different Society at that time, not only in medical matters.

MR MORRISON: No, indeed, in a wide sense.

LORD ARCHER OF SANDWELL: Sorry, you said there were two questions you wanted to ask?

MR MORRISON: Yes, I really wanted to check what commitments have been made by the Government to assist with the inquiry. We know of Jack Straw's assurance to Parliament of 19th April that there would be full co-operation, and one of the points we are particularly keen to see is that a number of people have come here in public and given personally distressing testimony. It would sit very badly with people if there was Government co-operation but not in public, so is there a commitment for the Department of Health to attend and give evidence in public; where are we up to with that?

LORD ARCHER OF SANDWELL: I will try to summarise the position. Up to this stage we have had only one meeting with officials from the Department, with the blessing of ministers, and we sorted out some of the initial queries required to be addressed.

Both sides left the meeting saying if at any time you wish to come back please feel free, we will respond, and that is the position at the moment.

Up to now, we have been doing a lot of reading and hearing a lot of oral evidence, and we are almost at the point I think where we would want to go back to the Department.

They have written now this last -- a fortnight ago, yes, because there was a holiday in between, asking us one or two questions, to which we will be replying, but we actually have not had another meeting yet.

I think perhaps I should say this publicly: we have seen a letter written by someone in the Department to -- I needn't say who it was -- but saying that the Department had sought a further meeting with us and had received no reply. I don't know how that came to be written, I don't believe that anyone in the Department deliberately arranged to tell a lie, but certainly it doesn't represent the facts. Neither side, up to this stage, has asked for another meeting.

MR MORRISON: Would any further meeting be held in a public arena such as this?

LORD ARCHER OF SANDWELL: I think we can't compel the Department to give public evidence, of course. If they were to say -- this is purely speculative -- we are happy to meet you, but we don't want to meet you in public, we would have to choose whether not to meet them at all or whether to meet them confidentially but that hasn't arisen yet.

MR MEHAN: To clarify that point regarding the Department's position, they have asked us whether they can be of any further assistance not whether we want another meeting. There is a distinction.

LORD ARCHER OF SANDWELL: I think in that letter there was something saying they would like to know when we would be publishing our report.

MR MORRISON: If I could follow on from that as well in terms of the making a variety of papers and information available, which has also been a commitment -- what is the latest understanding on the timeline for when that will complete, in terms of monthly release of documentation, because I presume that is material to when the inquiry can conclude and produce their report?

LORD ARCHER OF SANDWELL: We had the documentation for which we have asked up to now. We were given the documentation set out in their review which you may remember, so that at the moment there hasn't been any question about asking for anything which has been refused.

In relation to the documents which disappeared, we haven't yet had an opportunity to investigate that in detail. I think we may want to deal with that.

MR MEHAN: As I understand it, this morning the Department said by tomorrow they will deliver the documents that were sent back to by the firm of solicitors that we have all heard about, those missing documents, so we should get a full copy of those tomorrow. I think it is another few months that they are gradually releasing all of their documents. I think there are some 20,000.

MR MORRISON: That is the timeline I was specifically interested in.

LORD ARCHER OF SANDWELL: So it may be too late for our report, on the basis that everybody wants to hear our report as soon as we can reasonably produce it.

MR MORRISON: Indeed. I think it probably comes under the heading of "we don't know what we don't know until it is released". None of us can tell how material that is until we see it.

LORD ARCHER OF SANDWELL: There was one instance of another inquiry similar to ours when I think they delivered two van loads of documents which is a way to bring any inquiry to a full stop, I suspect. I hope that doesn't happen.

MR MORRISON: No, quite.

The only other thing I was going to say is that we are working through the transcripts from yesterday's hearing. A number of us were here yesterday -- I wasn't myself -- and if there are any points which we believe require some clarification, as we have done previously, we will come back to you with that.

LORD ARCHER OF SANDWELL: That will be mutual, I think, because when we have had time to co-ordinate all the information we have had, there may be some further discussions.

MR MORRISON: If I could just publicly thank you all again for your efforts in this. It is tremendously appreciated.

LORD ARCHER OF SANDWELL: Thank you for all you've done.

DR NORMAN JONES: Thank you.

MR MORRISON: Thank you.

LORD ARCHER OF SANDWELL: I think the next witness is a Mr & Mrs Hilary?

MS JUDITH WILLETTS: I wonder if we are slightly early.

LORD ARCHER OF SANDWELL: I wonder if Mr O'Mahony would mind proceeding now, and if Mr & Mrs Hilary arrive later they can --

MS JUDITH WILLETTS: Does anybody know if they are actually in the room or in the vicinity?

LORD ARCHER OF SANDWELL: If they were I imagine they would have made themselves known by now.

MR BRIAN O'MAHONY (called)

Good afternoon, Mr O'Mahony.

MR O'MAHONY: Good afternoon.

LORD ARCHER OF SANDWELL: Thank you very much for coming.

I think the easiest way would be if you wouldn't mind making your presentation and we can intervene as and when it arises.

MR O'MAHONY: My name is Brian O'Mahony. I have haemophilia B, sero-haemophilia B. I am currently the chief executive of the Irish Haemophilia Society and I was a board member of the Society from 1982 until 2003, so I was there right throughout the development of the whole AIDS situation and I was chairman of the Society from 1987 to 2003. I was also president of World Federation of Haemophilia for 10 years from 1994 to 2004.

In terms of percentages, you know, you are looking at a population of people with haemophilia about one tenth the size of the UK, but a similar percentage is affected with HIV and hepatitis C. We have approximate 400 with haemophilia in Ireland, and 104 were infected with HIV and 65 of those have died, about two thirds, which I believe is a similar proportion to here. 221 were infected with hepatitis C and 26 of those have died.

Obviously the vast majority of those with HIV were also co infected with hepatitis C and we are aware of only one individual who was infected with HIV who was not infected with hepatitis C.

MR MEHAN: Can you speak up a little?

LORD ARCHER OF SANDWELL: Do you know whether that has been the experience in most other countries?

MR O'MAHONY: Yes, I believe so. It is very rare to find someone infected were HIV but not hepatitis C, unless they had perhaps someone with mild haemophilia, who received one treatment or two treatments.

You were talking about May 1983. I came on board the board of the Irish Haemophilia Society in October, November 1982 as a new board member, and I raised concerns in early 1983 with the board and I raised concerns at the time with our own blood transfusion service and clinicians in relation to our concerns about both AIDS and hepatitis and indeed at that time we were in contact with the UK Haemophilia Society and noted they had similar concerns in relation to AIDS and hepatitis at the time.

Back in 1983, right up to, I suppose, 1986, 1987, the Irish Haemophilia Society was a very small organisation. I would equate their resources almost something similar to a residents' association.

When I was joined up, I was informed that I was being made honorary secretary and therefore all the mail would go to my house because there was no office, no staff, no resources. The annual budget was about £6,000. The Society raised concerns, as I say, in early 1983 in relation to AIDS. As things progressed and it became clear that many of our members were HTLP antibody positive, we started distributing condoms to our members, which of course was in contravention of the law in Ireland at the time, because as you know people in Ireland don't actually have sex, and therefore condoms were not available legally without going to get a doctor's prescription and the fact that we did distribute the condoms outside of the healthcare system and the fact that the healthcare system could not provide the distribution actually meant that we had no seroconversions of any of the partners with HIV, which I am very glad about.

In 1987 we conducted a full survey of all of our members with HIV to find out what their requirements were and they were very similar in fact to the requirements that the UK Society were finding at the time; lack of life insurance, no mortgage protection, inability to have a high protein diet, inability to meet the cost of hospital visits, so on and so forth.

We asked our Government at the time to intervene and make provision for these areas, but in the absence of being able to do that we asked them to set up with a trust fund and in 1989, following, I would say, a long campaign with the Government they did eventually agree, following a General Election, to set up a trust fund called the Haemophilia HIV Trust.

LORD ARCHER OF SANDWELL: As we have been hearing about this -- you may have been in the room -- from your point of view it was second best, was it?

MR O'MAHONY: At the time, yes, we would have been much happier if they had provided the dietary supplements, the mobility supplements, the hospital care at the time. This was really fire brigade money because people were dying at quite a rate. They weren't able to have a high protein diet, they weren't able to cover the costs of their visits to hospital, so the trust fund was established to actually allow for that, without having to go through an enormous bureaucracy, in the sense that if somebody was ill at home, and they needed a special mattress, they would get permission for this two months after they died. So this allowed for this to be done very, very quickly. In fact it was very similar, the HHIV Trust was very similar in scope to the Macfarlane Trust that was set up in the UK.

In 1991, again I think very much in parallel with what was happening in UK people with haemophilia, with HIV in Ireland, had been taking legal action and that legal action was settled following again a campaign. The Government agreed to pay compensation to people with haemophilia who were infected with HIV. The sums paid were broadly similar to the sums paid here at the time in the UK to individuals.

LORD ARCHER OF SANDWELL: This may transfer to be important in a rather different context. Was the money which was paid a settlement of a legal claim?

MR O'MAHONY: No, what it was, in fact -- at the time back in 1988/89 quite a large number of people with haemophilia issued proceedings against both pharmaceutical companies and the Irish government and this in fact, the payment by the Government was conditional on them dropping the suit against the Government.

LORD ARCHER OF SANDWELL: I suppose it could be argued it was in effect a block settlement of a number of claims.

MR O'MAHONY: The payments were made very clearly on an ex gracia basis without any admission of liability, but having said that, if someone wished to continue to take legal action against the Department of Health they wouldn't have received the payments, so those payments in 1991 were made on an ex gracia basis, but they did settle legal claims against the Government at the time.

LORD ARCHER OF SANDWELL: I see.

MR O'MAHONY: But they should not be confused with later HIV compensation which was granted in 2002 and I will come back to that.

MR MEHAN: Brian, you have figures here. Can you quote them?

MR O'MAHONY: The compensation paid at the time in Irish pounds, a married man with haemophilia, the children received £101,000; £94,000 to a person with haemophilia who was married with no dependent children, £77,000 to a single adult or child, and £20,000 to the parents of a deceased person. So those were the payments made in 1991.

From 1992 onwards hepatitis C was becoming an increasing concern to the Society and to our members. The clinical manifestation of hepatitis C was becoming apparent in more and more of the members and in 1994 we began discussions with Department of Health officials in relation to provision of treatment with Interferon, which was the standard treatment at the time.

But at the same time in 1994 we also began discussions with the Department on hepatitis C compensation, and those discussions on compensation, the discussions on treatment were resolved satisfactorily very, very quickly. The discussions on compensation between ourselves and Department officials continued during the course of 1995 and by late 1995 we had reached agreement on the setting up of a non-statutory compensation tribunal where each person with hepatitis C would have their case heard and assessed on an individual basis.

We had discussed that option. We had also discussed across the board ex gracia payments, but the option that was agreed was a compensation tribunal and that was set up in 1995.

LORD ARCHER OF SANDWELL: Can I ask you this, because again this has a risk: the word "compensation" is used all the way through this, including the title of the Tribunal.

MR O'MAHONY: Yes.

LORD ARCHER OF SANDWELL: Compensation is sometimes thought to represent a payment by someone who is responsible for the condition; presumably that was not the position here, it was a response to a need, rather than compensation for a wrongdoing?

MR O'MAHONY: I think it was -- you know, there has always been a long debate in the haemophilia community about whether to use the word "compensation" or "recompense". To the majority of people what matters is if you actually get sufficient financial resources to allow you to live but in fact I would say the word "compensation" was used deliberately because even though it was paid without any expression of liability, I think it was very clear that they felt a moral responsibility, that they felt that this was a disaster which had befallen the community and they were making provision for that and the compensation was also paid to persons who were infected with hepatitis C through blood transfusion and through the provision of anti-D, and also to patients who had been infected following kidney dialysis treatment. So there were four distinct groups of patients.

LORD ARCHER OF SANDWELL: But there was a discussion as to whether that word should be used, was there?

MR O'MAHONY: Not really. I can vividly recall my first discussion with the department officials on this, where they refer to it as "the C word", but the word "compensation" was used right throughout this, but it was not -- it was a non-statutory tribunal at the time and there was no admission of liability, as such.

In effect, it was almost as if you had an assessment of damages, because they assessed each case individually in relation to pain and suffering, in relation to state of health and relating to loss of earnings and so on and so forth.

So that was on a non-statutory basis. The first case was held in March 1996 and the first awards were made at that time and again. I want to emphasise the points that Roddy made earlier, that the first compensation payments were paid in March 1996 and this was well prior to both the Finlay Tribunal and the Lindsay Tribunal inquiry.

By July of this year payments had been made to some 2,200 claimants.

DR NORMAN JONES: Can I interrupt a moment on that figure? It is probably just stupidity on my part, but I am having some difficulty reconciling that figure with the total haemophilia population of 400.

MR O'MAHONY: As I say, there were four cohorts of people: persons with haemophilia, persons infected through blood transfusion, persons infected through anti-D and persons who had been infected through dialysis.

LORD ARCHER OF SANDWELL: So if someone claimed for two separate headings, you're treating it for this purpose as two claims?

MR O'MAHONY: Nobody really claimed under the two separate headings, but in fact -- you had 220 people with haemophilia. You had about 1,000 people who received anti-D, you had a couple of hundred people who were infected through blood transfusion, but that figure would also represent spouses, would represent carers, would represent dependants, so there have been payments made to others, as well.

MR MEHAN: You mentioned another tribunal other than the Lindsay Tribunal. What was that again?

MR O'MAHONY: That was the Finlay Tribunal. I will come back to that.

By July 2007 payments had been made to some 2,200 claimants, and again I would emphasise that the payments at this point have been extended, not just for the purposes of hepatitis C and HIV but to their spouses and carers and others. The total paid to date is 778 million euros.

That is -- these are the figures from the Department of Health. If you were to average that amount over 2,200 you would come up with an average payment of 353,636 euros, but the payments ranged enormously, and they have ranged from 14,000 euros to 3.1 million euros in individual cases.

Those figures were Department of Health documentation. The Compensation Tribunal publishes an annual report which gives very precise figures but the 2005 annual report is the latest available, and the 2005 report, the average award for that year was 143,647 euros. The range of awards in 2005, ranged from 14,000 to 1,624,383 euros, and the major difference, in fact, between those -- because it is an enormous variation --

would be a potential loss of earnings, so a young person with a very large potential loss of earnings would have the potential award.

MS JUDITH WILLETTS: These are ongoing. I assume there is a sort of natural end to the claim process?

MR O'MAHONY: Well, I will come back to that because in fact the claim process is not just the same process that started in 1996 -- they have extended that. If I can just go through that, I think it would become clear.

MS JUDITH WILLETTS: Sorry, yes.

MR O'MAHONY: Following the initiation of the compensation scheme, a tribunal of inquiry, the Finlay Tribunal was established and the hearings were held between October and December of 1996 and the Tribunal reported in March 1997. Now, we actually withdrew from the Finlay inquiry in December 1996 because it was clear that whereas the terms of reference initially looked as if they would deal with our issues it was very clear, in fact, that the terms of reference were being interpreted in such a way as to exclude the persons with haemophilia, with hepatitis C, and it was primarily devoted to looking at infections through anti D and to a lesser extent, through blood transfusion.

We then entered into separate negotiate equations with the Department of Health in relation to setting up a separate inquiry into all aspects of the infection of persons with haemophilia, with both HIV and hepatitis C, and the Department clearly recognised that the Finlay inquiry's terms of reference, as they were being interpreted, did not deal with that, and this latter tribunal, the Lindsay Tribunal, the discussions on the terms of reference took a long time, took from 1997 to 199 to get the get the exact terms of reference in relation to what was going to be covered and this tribunal of inquiry, the Lindsay tribunal, was established by the Parliament on 8th September 1999 and sat for 196 days from 27th September and 28th November 2001 and the report was issued in December 2002.

Prior to the publication of the Lindsay report but following the personal testimony at the inquiry -- and this is important, because quite a few people, similar to here, a lot of people with haemophilia gave personal testimony at the Lindsay inquiry and prior to any report being issued, the Government had re-entered discussions with the Irish Haemophilia Society. They had recognised that the HIV compensation paid in 1991 had been neither fair nor equitable, so they therefore passed an amended hepatitis C compensation bill in 2002 to allow for further compensation for persons with HIV.

Crucially it also allowed, for the first time, for adequate compensation for the widows of those who had died, prior to the first settlement being made, because we always felt that in 1991 when compensation was paid, if a man with haemophilia received £101,000, if he died a week before that, his by widow or his parents received £20,000 -- the widow would receive the money, but there was an unfairness inherent in the system and I think that was recognised by the Government in 2002, so they broadened the scope of the compensation tribunal to include HIV as well as hepatitis C. I have to point out, which I haven't done, that the compensation tribunal was established in 1996 on a non statutory basis but it was placed on a statutory footing in 1997, that it was broadened further in 2002 to include HIV, but also to include other areas. It allowed for compensation for spouses, for partners, for carers, it allowed for compensation for loss of consortium, for loss the Society, for post-traumatic stress disorder, so there was a much broader range of compensation available, and that really is why they are ongoing, because you are really looking at from 1997 (inaudible) 2002 and each case is individually assessed, and that means medical reports, psychological reports, occupational therapy reports -- so there is quite of lot of documentation in relation to this. It is a slow process but very, very thorough.

MS JUDITH WILLETTS: It is a small point, but those original compensation payments, were they deemed by you to be about right, or did they appear to be somewhat arbitrary or somewhat strangely arrived at? I find it strange that, if you have children, you only get 7,000 euros more than if you haven't.

MR O'MAHONY: It was somewhat arbitrary and in fact I think one of measures as to how those figures were selected -- we looked at the UK compensation paid in 1991, where there was a difference made in different categories and selected somewhat from that. They were arbitrary, they were not adequate payments certainly, but given the situation at the time, the number of people dying from HIV was increasing dramatically and rapidly and they were facing this long interminable legal process where by the time it had finished nobody would be left alive. In 1991, it really looked as if everybody with HIV would be dead within three or four years, so the sort of compelling sort of thing to settle was there very, very quickly.

LORD ARCHER OF SANDWELL: It was quicker to short-circuit long arguments about whether some particular person would have earned £20,000 a year or 30,000 a year.

MR O'MAHONY: Absolutely.

MS JUDITH WILLETTS: They needed to take what they could, on the basis they didn't expect to live very long.

MR O'MAHONY: And in fact the figures were put to a meeting of all the people with haemophilia in terms of were they satisfied with the apportionment of that amount, and were they happy. The Government in fact just gave a block grant that was apportioned in that way, and the people with haemophilia themselves agreed with that so from that point of view it was satisfactory, but the amounts, in terms providing for families long-term, certainly were not.

MR MEHAN: Just to emphasise the point again, were they asked to sign waivers?

MR O'MAHONY: They were asked to sign waivers exempting the government and state agencies from litigation. The government were quite happy for them to pursue litigation against the pharmaceutical companies but not against they named Irish defendants.

They were not asked to sign waivers about hepatitis, mind you, which was the situation here in the UK, where they received HIV compensation they had to sign waivers for HIV and hepatitis, which even at the time I thought was bizarre.

The Lindsay Tribunal reported in September 2002, and I certainly don't propose to go through the report but just some of the major findings: again, 104 persons with haemophilia were infected with HIV. They identified two batches of Irish-produced Factor IX concentrate which were responsible for the infection of seven persons with haemophilia being with HIV, although the majority of the Factor VIII infections would have been due to imported concentrates.

The Blood Transfusion Service was found to be responsible for the infection of one person who required precipitate. One individual was identified as infected through a contaminated pharmaceutical product from the Armour Company which was a product actually that was withdrawn and then reissued and subsequently infected one person.

They found on the balance of probabilities that two thirds of persons were infected with HIV by the middle of 1983 and one third subsequent to that date. They found that a minimum of 217 persons were infected with hepatitis C. All products used for treatment of persons with hepatitis prior to 1990 were potentially infectious for non-A non-B hepatitis although to varying extents.

They also identified Irish Factor IX, which was responsible for the infection of seven individuals with hepatitis C. The Blood Transfusion Service were responsible for the delay in the introduction of heat treated Factor IX concentrates.

The Tribunal found that there was an ambivalence of the Blood Transfusion Service with regard to infections which had been caused by non-heat-treated products in 1985 and 1986, a reluctance to acknowledge that their product had been the cause of infection. In fact right throughout the discussion with the Department of Health in the early 1990s that ambivalence remained and it was very difficult to get information on that.

They also found that the numbers of consultant haematologists were inadequate and there were structural weakness in the medical administration of the Blood Transfusion Service.

LORD ARCHER OF SANDWELL: I will just clarify one matter, if I may.

MR O'MAHONY: Certainly, yes.

LORD ARCHER OF SANDWELL: "A reluctance to acknowledge that their product had been the cause of infection"; did that imply that they ought to have acknowledged it, or did the Tribunal simply say, "They didn't accept it and we can't go further than that".

MR O'MAHONY: The Tribunal were very gentle in their wording, they used phrases like "reluctance to acknowledge" and "ambivalence", but it was quite clear that the Blood Transfusion at the time constantly stated, "All of these infections were caused by imported products, our products were perfectly safe", and that in fact was not the case.

LORD ARCHER OF SANDWELL: Yes, I see.

MR O'MAHONY: In fact, I have just looked at some of the dates from the UK and I think if you look at areas like introduction of HIV antibody testing, hepatitis C antibody testing and so on, one person did say to me that the reason that compensation was paid in Ireland and not in the UK was that the Irish Government were culpable and the UK Government were not.

LORD ARCHER OF SANDWELL: Yes.

MR O'MAHONY: Well, in fact HIV antibody testing was introduced in the UK in October 1985 and in Ireland in October 1985; hepatitis C antibody testing was introduced in September 1991 in the UK and in October 1991 in Ireland, so the same dates.

In terms of self-sufficiency, which we placed a lot of faith in the early 1990s, in Ireland self-sufficiency was promised in 1980 and delivered to a limited extent in 1985. In the UK, it was promised in 1974 and delivered in 1987, so in fact there was a longer delay.

There were a lot of parallels between the situation. ALT testing, for example, in Ireland was going to be introduced in 1987, as a surrogate marker for hepatitis C, and they then decided to delay the introduction pending its introduction in the UK; of course it was never introduced in the UK so it was then never introduced in Ireland. So I think there were a lot of parallels in terms of the timing of those, no major difference.

The recommendations of the Lindsay Tribunal, if you look at the report, the recommendations cover two pages and we felt they were brief and somewhat general and really more principles than detailed recommendations.

Among the recommendations were that the blood products supplied to persons with haemophilia should be of the highest standard and of highest safety that were available; that a co-ordinating committee in regard to the treatment and care of persons with haemophilia should be established with representatives from the various different organisations and groups in relation to haemophilia care; and this should include all aspects of the care and treatment of haemophilia, including the choice of blood products to be given, and the Tribunal was of the view that it was essential that this committee be properly resourced and have adequate personnel and office facilities available to it.

The Tribunal also stated that consideration should be given as to whether it would be desirable to have the committee established under statute, to ensure its efficient and effective operation.

They stated there should be greater co-operation and exchange of information among the various doctors treating haemophilia, and that a sufficient number of consultant haematologists should be appointed to posts throughout the country; that medical records should be kept and maintained in a more satisfactory manner; that complete and adequate national statistical records should be maintained at the National Haemophilia Treatment Centre; that doctors should ensure that test results in relation to patients are given to the patients as soon as the results become available; and that the Irish Blood Transfusion Service should establish protocols to ensure that if in the future new tests became available for infective agents a positive result of any such test would be communicated to the relevant donor as soon as possible.

The Tribunal decided it was not its function to decide issues of criminal or civil liability, and therefore it did not forward a copy of its report to the Director of Public Prosecutions.

Judge Lindsay also noted that the minister had commissioned a separate report in relation to the feasibility of holding a further inquiry into the role of international pharmaceutical companies and therefore she would not make findings in relation to that area, and she also noted in her report that the minister and the Irish Haemophilia Society had reached agreement in regard to further payment of compensation for persons with HIV and therefore she did not need to make any recommendation with regard to compensation.

If I can go on to the impact of, I suppose, the Tribunal on the Irish haemophilia community, there was initially a high degree of disappointment with the report among persons who were infected with HIV and hepatitis C. It was felt it was very vague and non-specific; the language it was felt was somewhat woolly; the recommendations were very general.

We were able to utilise the general recommendations very effectively, because we had submitted to the inquiry very strong recommendations for the future, and you know, where the chairperson said that this committee should be set up we were able to work with the Department to set up the terms of reference for that very effectively.

LORD ARCHER OF SANDWELL: But there was a general expectation that the report would be in more dramatic language.

MR O'MAHONY: Yes, and that the recommendations and the findings would be clearer and that the recommendations would be more specific.

LORD ARCHER OF SANDWELL: Yes.

MR O'MAHONY: But I think the process and the period leading up to the Tribunal were very important to the community for a number of reasons. First of all, many people with haemophilia were able to attend the inquiry and hear at first hand evidence in relation to, you know, the disaster that had befallen them, and going right back to the mid-1980s, when people were dying, when they were dying in secret, when they were afraid because of guilt, anxiety, fear of stigma, fear of discrimination, they were afraid to disclose to their friends, to their family, to their neighbours they had HIV -- this was a hidden disaster, it was hidden.

I can remember talking to a man who was trying to decide what to tell his two children before he was dying and he eventually settled on telling him that he had cancer, because if they knew the truth his children would have been ostracised, they wouldn't have played with other children. So all this was hidden. This was very important, that this was public. They went along, they were able to go along and give evidence in a public forum, which was hugely important.

DR NORMAN JONES: Excuse me, can I take up that point? Looking back on it now, was it really effective at destigmatising the situation?

MR O'MAHONY: Yes, absolutely, because I would venture that if you did a survey in Ireland you would find that a minute proportion of the population have read the Lindsay report, as with any tribunal report in one sense. But the coverage in the media was very constant and it educated the public about haemophilia, about HIV and hepatitis C. It educated them as to what had happened and people felt much freer in terms of saying "This happened to me", and so on and so forth.

We had many individuals who gave personal testimony. There was a facility for them to do this anonymously or, you know, giving their name and details, and interestingly enough, a couple of people, who had decided to give anonymous testimony, when they started to see the public coverage, changed their minds and said, "Look, I am going to tell people about this, I have nothing to be ashamed of", that was actually very effective. I think for the individuals who gave personal testimony, speaking to them afterwards, many of them felt it was cathartic, that it really did help them to try to bring some closure in relation to this.

It was an acknowledgment that their story was being listened to, was being heard. It was very, very important for them, and it did lead to a much greater public understanding of the situation that had befallen people with haemophilia, and that got rid of the stigma, it got rid of the discrimination in many cases, and there was a lot of sympathy.

Following the Parliamentary debate on the inquiry report, the minister for health and children in the Parliament publicly acknowledged what had happened and issued an apology on behalf of the Government for the persons with haemophilia who had been affected and that was very, very important for them and he was -- he took great care to ensure that as many of the persons with haemophilia possible were present in the public gallery when he made the apology. It was very important for them.

MR MEHAN: Do you know the terms of that apology?

MR O'MAHONY: It is in the record of the Parliament, we can certainly get that for you.

MR MEHAN: It would be hugely interesting, what they were apologising about and for.

DR NORMAN JONES: Following that line, there is a viewpoint -- I am not necessarily saying I share it, but there is a viewpoint that such public apologies by governments for things that happened long past are absolutely ridiculous. There is no way that the people who make the apology had any influence on what happened in the past, even though they may be the successors in post. You are really saying that that is not true?

MR O'MAHONY: I am. I think you have to look at the amount of time that has elapsed. I think Tony Blair, when he addressed the Irish Parliament, apologised for the actions of Elizabeth I; that is four hundred and some years ago. The Danish ambassador recently apologised to the Irish people for the Vikings; that is going a bit far back. This is 20, 30 years ago.

LORD ARCHER OF SANDWELL: This has given some rise to some debate about it.

MR O'MAHONY: I think it is very, very important. The ministers who are there now, they were junior Members of Parliament, they were there, getting involved politically. This is not something that happened in the Victorian era, this happened in the last 20, 30 years, and I think an apology -- you are talking about things that happened in all of our lifetimes and their lifetimes and I think an apology is very much warranted in that situation.

LORD ARCHER OF SANDWELL: Of course there is a problem about issuing an apology for something when you are denying liable for it.

MR O'MAHONY: Absolutely, and the lawyers would readily say to them, "You should be very careful about apologising, because that has its liability". You know, in Parliament, Members have absolute privilege, and I think it is correct to use that to lay the truth out there and if the Government has made a mistake and they are responsible for something like this, they should say so.

DR NORMAN JONES: And it can be reassuring that someone is capable of saying sorry.

MR O'MAHONY: Yes. I wouldn't underestimate its importance. I think it was very important for the community.

In the same Parliamentary debate the minister did say that -- and I can't remember the exact words, but words to the effect that no matter what happened with the Irish Health Service in the future there would be no question of cutting back on the quality of care available to people with haemophilia because of what happened in the past, so that was important as well.

DR NORMAN JONES: Thank you.

MR O'MAHONY: We had submitted our recommendations for the future to the Lindsay Tribunal and that included recommendations for a formal involvement of the Haemophilia Society in the future selection of blood products and in the formal involvement of the Society in relation to policy decisions on haemophilia, and recommendation number 2 of the Tribunal was the setting up of a co-ordinating committee in regard to treatment and care of persons with haemophilia, and I think in 2001, following representations from ourselves, a haemophilia products selection and monitoring advisory board was established on a non-statutory informal basis, initially, and following the report of the Lindsay Tribunal this haemophilia product selection and monitoring advisory board, which was basically a tender commission, was set up on a formal basis and that has been operating since 2001.

I will come back to that later in more detail, if I may.

A National Haemophilia Council was established on statutory basis in 2004, to advise the minister for health and children and to make recommendations to the minister and all appropriate bodies in relation to all aspects of haemophilia care.

In relation to recommendation number 4, on more consultant haematologists; number 5, medical records; and number 6, accurate statistical records, a lot of progress has been made.

The National Centre for Hereditary Coagulation Disorders has been more adequately resourced as a result of the report and the regional centres and the national centre have appointed several new consultant haematologists since the Lindsay Tribunal, in addition to more nurses, psychologists, social workers and other specialist healthcare staff.

The Department of Health and Children maintains a separate budget to allow for implementation of recommendations of the Lindsay report. So, for example, if a particular post has been asked for, requested, they say "We actually can budget for this under recommendation number 4 of the report".

MR MEHAN: Can I ask, do haemophilia patients now receive counselling?

MR O'MAHONY: Yes.

MR MEHAN: Did they before?

MR O'MAHONY: In 1980s and 1990s, very very little counselling and the vast majority of the counselling they received would have been from staff employed by the Irish Haemophilia Society. But there were more adequate counselling services available.

In addition, an electronic patient record system has been implemented by the National Centre and an IT system is currently being implemented to link the National Centre with eight other centres around the country where treatment is provided, so that any person with haemophilia, going into any one of nine hospitals, would be able to have an electronic swipe card which would record all of their relevant clinical details on that so they would be able to get treatment in those areas, where their details are known.

The recommendations have been used with clinicians in accessing more resources for treatment and care of all persons with haemophilia.

I think that the setting up of the Tribunal in itself was a manifestation of the recognition by the Irish Government of the uniquely tragic nature of the infection of so many persons from one small group in the community with HIV and hepatitis C, and I don't believe that all of this flowed as a result of the Tribunal, I think the Tribunal was one manifestation of their recognition of this disaster, and there was a number of actions taken by the Government which made it clear they recognised the nature of the disaster.

In 1997, at the time when we were just discussing the terms of reference for the inquiry, the Government agreed the provision of recombinant products for all persons with haemophilia on an ongoing basis, and I think it was an acknowledgment of the reality that any subsequent inquiry or tribunal would inevitably find that persons with haemophilia had been exposed to too many unsafe blood products in the past and in the future they should always have access to the best available products at any given time. So they implemented the recommendation even before the recommendation was made, if you like.

Hepatitis C compensation was granted from March 1996 to a non-statutory tribunal and this was then placed on a statutory basis in 1997.

A hepatitis C consultative council was set up to advise the minister on all aspects of policy in relation to hepatitis C in 1996, and the Society is represented on this council which does extremely good work, including now the organisation of the international conference on hepatitis C, totally funded by the Irish Department of Health every second year.

The enactment on a statutory base in 1996 of a Health Amendment Act gave additional entitlements to additional health services to people with haemophilia who had been infected with HIV and hepatitis C through blood and blood products supplied by the state, and I will come back to that.

The setting up of the haemophilia product selection and monitoring advisory board allowed people with haemophilia a full formal role in the selection of products in the future.

The setting up of the statutory National Haemophilia

Council allowed the Society a formal role in policy in relation to haemophilia.

Additional Government funding for the Irish Haemophilia Society was granted. In 2003, the annual grant from the Irish Government for the Society was doubled from 300,000 euros to 600,000 euros. This represents 90% of our funding on a ongoing basis.

The establishment on a statutory basis of an insurance scheme for persons who had been infected with HIV and hepatitis C. This bill was passed in 2006, and the regulations were passed in January of this year, and the scheme will be coming into operation actually next month, in September.

Let me just say a few words about these various areas. In relation to provision of recombinant products, recombinant products have an exemplary safety record. There has not been a single viral transmission of any sort from any of the recombinant factors since their introduction in 1994, and I think that the real fear among people with haemophilia -- I think the products available now, the plasma-derived concentrates available, are certainly safe from the hepatitis and the HIV. The real fear is the next virus. If SARS or West Nile could have been transmitted through blood products, it could have been another disaster.

But if there is another virus out there which is impermeable or not inactivated by the current viral inactivation techniques, then that could hit the community again, and people with haemophilia, if you are going to have a blood-born virus, they are always going to be hit because of the large pool of products that they use. So I think it was very much a source of great comfort to people with haemophilia that recombinant treatment products were made available 10 years ago and have been available since, and I think the provision of these products on an ongoing basis is in line with stated Government policy now, that cost will not be allowed to be the sole deciding factor in relation to the provision of haemophilia treatment in the future. Of course it is a factor, but it is not going to be the sole deciding factor. Safety, efficacy and quality will be paramount.

The product selection and monitoring advisory board meets six times per annum. This is the tender commission. It includes three clinicians, two representatives from the Irish Haemophilia Society, including myself, representatives from the Department of Health, the Health Service Executive, the Blood Transfusion Service, a virologist and a couple of other experts.

We have two representatives on the board and we are also allowed to nominate our own external expert, who can accomplish us to any meeting that we wish.

I currently serve as vice chairman of the board, and the board has been very successful. We have carried out seven tenders since 2003 for the purpose of recombinant Factor VIII, recombinant Factor IX, and a plasma-derived concentrate for the treatment of von Williebrands and Factor X deficiency. So we still have to deal with plasma derived products for those other conditions.

LORD ARCHER OF SANDWELL: Does this principle goes so far as to say that cost doesn't enter into the choice at all?

MR O'MAHONY: No. It is a factor, Lord Archer, but I think you will find that -- and I have studied the tender process in many countries and produced a guidebook for WH. In many countries, cost is the only factor.

LORD ARCHER OF SANDWELL: Sure.

MR O'MAHONY: For example, in Bolivia, the officials who choose the blood products also choose the paperclips. Now, if you buy bad quality paperclips a cut finger is probably the worst thing that can happen. You can't have the same thing applying to Factor concentrates. So I think you have to have a balance.

In developed Western economies where we are not poor countries I think you can say that of course cost is a consideration, but you must look at safety, efficacy and quality, and provided you are looking at safety, efficacy and quality, and if you are looking at two products of similar safety, efficacy and quality, and one of them is significantly cheaper than the other, then certainly you chose the cheaper one.

We have actually published our selection criteria, it is very open and transparent, and we had, I think, for our last recombinant tender we had a 220-point scale for checking out each product, and cost came to just under 20% of the total score. So really, you know, if -- an unsafe product would not even be considered.

What we tend to do is a two-stage process. We would look at the products -- let's say we get six products, six companies tender for six products. We will look at these and decide that four of these six meet our standards in relation to safety, efficacy and quality, and then we will look at cost. But cost is not the sole criteria.

MR MEHAN: Can I ask, are you looking at products on a regular basis? Are new products being developed all of the time?

MR O'MAHONY: Absolutely, and the commission does not just meet when we are doing the tender, because then we would be out of date. We actually meet six times a year and we keep up to date with developments and there are new products being developed and we get briefings and information on this.

MR MEHAN: Are you talking about product in relation to treatment of haemophilia or hepatitis C and HIV, or a combination of all three.

MR O'MAHONY: No, haemophilia, Factor VIII, Factor IX deficiency, von Williebrands, Factor II, VII, X, XIII; the rare bleeding disorders. Not HIV or hepatitis C treatments, it is not within the remit of the commission. It is replacement products for treatment of haemophilia and von Williebrands and rare bleeding disorders.

MS JUDITH WILLETTS: Recombinant treatment, because of the way it is manufactured, produced, must be safe from future unknown viruses, must it not?

MR O'MAHONY: You know, there is always a possibility of contamination. Look at the foot and mouth thing a few weeks ago from a laboratory. You can always contaminate any product.

MS JUDITH WILLETTS: Okay.

MR O'MAHONY: It is hard to see how you would get a human virus in a recombinant product, but there were concerns around zoonosis and animal viruses and using Chinese hamster cells and so on and so forth. So I think, you know, one thing that I think people think they have learned is that nothing is ever 100% safe, you will never take that as being read, and I think you also have to look at inhibitors as a potentially serious side effect of treatment, and there are some concerns in relation to the risk of inhibitors.

MS JUDITH WILLETTS: Yes, I understand that.

MR O'MAHONY: We will look very, very carefully at all of the criteria, and when you are doing a very full tender process like this and you are examining all of the products fully, and we have very, very specific criteria, we demand all of the information from the companies, and then we have a very, very good discussion and what has been really interesting is the way that every single person in the room will contribute to the discussion and then we will come to a consensus on the score for each product in each area, and it has been a remarkably successful process.

I think if you were to talk to the Department of Health officials they would be probably quite concerned about this initially, thinking this would maybe be a woolly process, maybe too elongated, and also would cost more. They were very pleasantly surprised; the first major tender came in about 4 million euros under budget, because we made the process more competitive.

The process in the past would have been they would have discussions with one company at a time. We had them in one hour after the other, they were each given 45 minutes to present and it was made very, very clear, "You are now in competition, the cosy arrangements of the past are gone", and I think the prices actually came down, which was interesting.

I think it has been a very, very good process, to the extent I was asked by the World Federation to produce a guidebook on national tenders. I produced that in 2005, and it is now becoming an increasingly recognised trend in developed and developing countries that if you are going to have a tender process for the purchase of Factor concentrates then you must involve representatives of the National Patient Association if you are going to have a good process.

This is not only in Ireland, as I think I have already said: Canada, Australia, Japan, Brazil, Uruguay, Georgia, Thailand are among the countries now who have the Haemophilia Society involved in the tender process.

MR MEHAN: Can I ask you to slow down a little bit more?

MR O'MAHONY: The co-ordinating committee that Judge Lindsay referred to, she said that it should look at all aspects of treatment and care, including choice of blood product, and we clearly set up the choice of blood product in a separate body, which was the tender commission. The co-ordinating committee is the National Haemophilia Council. This was set up on a statutory basis in 2004 to advise the minister and to make recommendations in relation to the care and treatment of persons with haemophilia, protocols for treatment, health services for persons with haemophilia, education and training of staff to provide services for persons with haemophilia, education and health promotion for persons with haemophilia and their families, and the changing needs of haemophilia in order to ensure that the Health Services respond effectively to those needs, developments arising from research, and appropriate support service for the families of persons with haemophilia; very broad-ranging terms of reference.

The Council includes three commissions, a specialist haemophilia nurse and two representatives from the Irish Haemophilia Society, including myself. There are also representatives from the Health Service Executive and from the Department of Health and Children.

The Council has been very successful. It has been responsible for the production of national treatment protocols which were produced in conjunction with the clinicians and the haematologists throughout the country. They have been responsible for the recommendation and priority allocation of resources for the different haemophilia treatment centres.

That is an interesting point, because this is something that the Department Health very quickly saw the advantage of. You have now got three haemophilia centres, each of them saying, "Please, we need a new haematologist, we need an extra haematologist", and they can now throw this back in the lap of National Haemophilia Council and say, "Okay, we now have three of the centres saying that they want a haematologist; you tell us which is first priority, which is second, which is third", and you now have the doctors, the Department and the patient organisation making that representation together.

And they have seen the advantage of this, because this gives them a certain amount of cover, if you like, for the decisions they are making. And we are happy with that, because this means there is full participation in the decision-making process.

The Council is involved in auditing at the centres. We carried out a very good look back programme for HIV and hepatitis C, where we ensured there was nobody in the country who would receive concentrates who had not been tested for HIV and hepatitis C.

We did a national information programme on the risk assessment for variant CJD following the risk assessment in the UK in 2004, because quite a few people in Ireland had received products in the UK over the years, and the Council also wants annual information days. Last year we had a very good information day, for example, on the future. We had three speakers all taking different views on what the future holds.

The Council provides an ideal form for ongoing co-operation between clinicians, the patient organisation and the Health Service in relation to optimising the utilisation of resources available for haemophilia and then prioritising areas for further improvement.

Interestingly, the Council can also act as an appropriate forum for discussion of potentially contentious issues in a non-adversarial environment.

DR NORMAN JONES: Can I stop you there? Have there been instances of that?

MR O'MAHONY: Absolutely, there have been arguments about, "This should not be the policy, that should be the policy", where there have been complaints about the service being provided by a particular hospital. Where these had not resolved in discussions between the clinicians and the hospital and the Society, they would be taken to the National Haemophilia Council and all of the situation would be fully teased out and recommendations made. It has worked, it has worked very well.

There are always going to be tensions, there are always going to be differences in emphasis and you know, different expectations about what the service could and should provide and the Council gives you a forum where they can be discussed, debated and decided without people destroying the relationships that are there.

In fact, I think you were asking earlier, Lord Archer, about the differences between the doctors and the Haemophilia Society and so on -- this type of forum, I think, works extremely well, because we will of necessity still have differences of opinion with the doctors and certainly with the health officials. But we can also get together and decide on coherent policy initiatives in a body like this.

DR NORMAN JONES: Looking like the range of activities which the Council undertakes, including such things as look back studies, what sort of size staff and secretariat?

MR O'MAHONY: Interestingly, the Council doesn't actually do the work, it is carried out under the auspices of the Council. So they would direct the centre to do this or in some situations there might be an information campaign the Irish Haemophilia Society might be asked to undertake.

To give you an example, it was realised that many new doctors and nurses coming into haemophilia care have never really seen the worst sequelae of untreated joint bleeding, so we produced a DVD where we had people who grew up in the 1960s and 1970s talking about the difference between growing up then and growing up now, and this has now been distributed to the doctors and nurses.

DR NORMAN JONES: So it initiates and facilitates, really.

MR O'MAHONY: Yes. There are two staff, and it has its own office, it has a staff, a small staff -- but it also gets crucial support from the Society, from the centre and from the Department of Health. It was made very clear in the recommendations at Lindsay that if you look back in the early 1980s, there was a National Haemophilia Committee in Ireland, but it was toothless and powerless, and you had the doctors and the Department of Health and the Haemophilia Society sitting in a room where basically, at the time, you were told what decisions had already been made and implemented and ideas would be put forward and nothing would ever happen; no staff, no resources, no follow through, and it was not an a statutory basis. It was basically an opportunity for people to get together for coffee four times a year and waste of time, really.

DR NORMAN JONES: Would the Irish Department of Health regard a recommendation from the Council as binding?

MR O'MAHONY: Not necessarily binding, but they would be very loath to dismiss it.

DR NORMAN JONES: They would have to have a very, very good reason.

MR O'MAHONY: They would have to have a very, very good reason. I think what they certainly will do is they will come back and say, "We been asked for resources in three areas, we can do one this year and one next year, what is your recommendation?" They don't have to take the recommendations, but I haven't seen them refusing the recommendation.

LORD ARCHER OF SANDWELL: Do you think the difference is largely that it is now statutory?

MR O'MAHONY: The difference really is the acknowledgment of what happened in the past meant that the situation has to be changed, so it is statutory, you have an independent chairperson, and a formal involvement by the Society.

Back in the 1980s, I attended a couple of meetings, and basically they were an opportunity where you could be told what had transpired in the previous three months. There were no decisions taken at those meetings. So I think being on a statutory basis adds tremendous weight to the committee. If it was non-statutory it is advisory, and advisory committees come and go. We had a particular minister for health back in the 1980s who if you wanted to not take any action you could always set up an advisory committee who would advise six months later when the issue had gone away.

LORD ARCHER OF SANDWELL: An old ploy, yes.

MR O'MAHONY: Yes. So I think the fact that this is there is important.

LORD ARCHER OF SANDWELL: I am not sure if I caught this, if you said it; are the meetings in public, or are they confidential?

MR O'MAHONY: The meetings are not in public, but the minutes are available to anybody who asks for them. The Council does not meet in public.

LORD ARCHER OF SANDWELL: I see, but the conclusions, the recommendations to the Government, are they made public?

MR O'MAHONY: Yes, they would be. Not in a constant manner. I guess -- certainly the minutes are available under freedom of information, the minutes are available to any of the clinicians who request to see them, the officials

... There is no nothing secret about the deliberations.

LORD ARCHER OF SANDWELL: If the Government said, "We don't accept your recommendation", it would be possible to make it public.

MR O'MAHONY: Absolutely.

LORD ARCHER OF SANDWELL: "This is what the argument is about".

MR O'MAHONY: If the Government did not accept the recommendation you would be reading about it in the newspapers, because it would certainly be made public. And in fact, Roddy was talking earlier about the need to have meetings with the secretary of state for health. We would meet them once a year just to present the annual report to the Council and we would meet on them on other occasions during the year when situations arise.

LORD ARCHER OF SANDWELL: And the annual report, of course, is made public.

MR O'MAHONY: Yes, yes, yes.

The Hepatitis C Health Amendment Act, I referred to the 1996 legislation which gave each person with HIV or hepatitis C a special card which they could use to facilitate faster and more flexible access to the Health Service, and the card entitles the person with hepatitis C or HIV open access to hospital facilities, including the right to a public hospital bed, prioritised access to see specialists, and prioritised access to hospitalised admission. And the card holders also are entitled to the following services free of charge: general practitioner visits, prescribed drugs for any condition, counselling, complementary therapies, dental treatment and appliances, home nursing services, home help support services, ophthalmic services and physiotherapy.

It is a very, very broad range, and what it basically serves to identify is the fact that a person with haemophilia who has been infected by HIV and hepatitis C, any subsequent health condition they have or will develop will either be as a result of that or will be greatly impacted by their haemophilia or hepatitis C or HIV.

DR NORMAN JONES: We heard earlier today from Mr Morrison a comparable list, really, drawn up by the Haemophilia Society as a recommendation, and it had in addition to the various aspects you have there, "Treatment overseas if necessary, (liver transplantation)", in the context of hepatitis C.

MR O'MAHONY: Yes, yes.

DR NORMAN JONES: You haven't.

MR O'MAHONY: We do. That is because I neglected to put it on the list. It is in fact available. For example, any person with haemophilia and HIV in Ireland, who is co-infected with HIV and hepatitis C, if he requires a liver transplant, it is carried out in London. Because the numbers are so small, it really doesn't make sense to have them done in Ireland.

In fact, there would be no problem -- we have had one person who enabled to have a liver transplant in the United States because their particular set of circumstances meant there was a better chance of success. So in fact there is a provision for treatment overseas.

DR NORMAN JONES: Thank you.

MR O'MAHONY: It is there.

I think what that legislation has meant, really, is that the person with haemophilia who has HIV or hepatitis C has not had to bear any burden of financial cost for their illness or for any other medical condition, and that has been really, really important. It is very important for the person with haemophilia, with hepatitis C and HIV to visit their doctor constantly, to be assessed constantly in relation to the state of their liver and their immune system, and that is not facilitated if they have to pay for treatment or if their ability to access that treatment is made difficult, and I think this legislation has been extremely important in terms of preserving their health as best they can.

The provision of insurance is being made at the moment and that Act was passed in 2006, and it allows for the provision of life insurance, mortgage insurance, remortgage insurance, for someone who has already purchased their house, and travel insurance, the idea being that the person with haemophilia, with HIV or hepatitis C, will be entitled to avail of life insurance, mortgage insurance and the other insurances at the same premium they would pay for a person their age who is perfectly healthy, and the Government would pay the additional loading.

It is envisaged that the people would be divided into two broad categories: you might have, for example, persons with hepatitis C, who are antibody positive, or perhaps PCR positive also, who would be loaded, so there would be an additional premium charge by the insurance company; the Government would pay the additional premium.

DR NORMAN JONES: In agreeing to pay this additional premium, do you know if the Government has been in consultation with various insurance companies?

MR O'MAHONY: In fact, yes. The implementation of the scheme is being put together by an insurance steering group and again I sat on that group and we have representatives on that group and we have been in consultation with a number of insurance companies. The scheme has been clearly set out to them and we have now got, I think, two companies who are going forward with the scheme at the moment. I think the idea is that they would pay the same premium that would be paid by a person their age who does not have any medical condition.

As I said, on one side you would have people who would be loaded and on the other side -- for example, we expect that many of the individuals who were co-infected with HIV and hepatitis C will be deemed by the companies to be uninsurable. In this case, the person will still be able to avail of mortgage insurance and life insurance and they will pay the normal premium that they would have paid if they were perfectly healthy, and the Government will basically assume the risk.

LORD ARCHER OF SANDWELL: Will assume the risk?

MS JUDITH WILLETTS: So the Government becomes the insurer.

MR O'MAHONY: In effect, yes. The person still pays their premium to Acme Insurance Company, and the Government makes an arrangement with them and in the event that the person dies, then the Government actually -- the payment comes through the insurance company but it is the Government --

MR MEHAN: They are underwriting it.

MR O'MAHONY: Yes. The insurance cover will be available up to the age 75 and travel insurance will also be provided under the scheme.

In the past, and as I said, going right back to 1988, we had clarified that it was very, very difficult for people with haemophilia and HIV, and indeed hepatitis C, to get any access to life insurance.

LORD ARCHER OF SANDWELL: Can you satisfy some curiosity when I read that? Why a cut-off point at 75? Is it that in fact that there are not likely to be any sufferers still alive at 75, or is it that at 75 you are probably uninsurable anyway?

MR O'MAHONY: I think it is the case that at 75 it is more difficult to get life insurance on any sort of decent premium, so they insisted on some sort of cut-off date. We were arguing for 95, but they wouldn't bite that one. In fact, if you look at the situation, if it wasn't for HIV and hepatitis C, if a person with haemophilia could get to the point where men generally start to have heart attacks you have an advantage, because your risk of coronary thrombosis a much lower if you have haemophilia. So I think the 95 was reasonable, but they wouldn't bite. But it does cease at the age of 75.

What this does, it in effect allows the people with haemophilia to make provision for their independence, and it is hugely important.

That scheme was difficult to put in place, it is quite novel, and it took seven years of discussion and negotiation to get that in place.

MS JUDITH WILLETTS: Yes, I am sure.

MR O'MAHONY: But I think if the UK Government would look at something similar, a lot of groundwork has been done; you have the same insurance companies.

If I can go on to funding for the Haemophilia Society, the Irish Haemophilia Society has received a substantial proportion of our annual funding from the Irish Government for the last 10 to 12 years and as I stated earlier, in 2003 this funding was doubled from 300,000 to 600,000 euros per annum. That is now some 90% of our annual funding requirements.

It is recognition that the Society provides a valuable role and provides unique and distinctive services for persons with haemophilia and related bleeding disorders. Without this funding it simply would not be possible for us to provide the advice, support, assistance, information, education, practical support and the programmes that we run for persons with haemophilia, including those with HIV and hepatitis C.

LORD ARCHER OF SANDWELL: From the Government's point of view, it is probably an economical way of providing those services.

DR NORMAN JONES: £400,000 a year.

MR O'MAHONY: Yes, they have looked at the fact that if they had to provide these services through the Health Service first of all it would cost more and secondly, many of them you just couldn't provide through the Health Service. I think they recognise it is cost-effective from that point of view. As I said earlier, the saving from the first tender alone was 10 years of that funding.

In terms of compensation abroad, I think in addition to Ireland compensation for hepatitis C has been paid in Canada, Hungary, Italy, New Zealand, Spain, Sweden, and in the UK to, in my view, an inadequate extent.

MR MEHAN: You don't mention France.

MR O'MAHONY: I don't mention France, you are correct. The list is not exhaustive. I think the French/Italy compensation is due to litigation, so I didn't mention that. Now, the French do make monthly payments to persons with hepatitis C. I haven't included there countries that make regularly monthly payments which include France and Italy. But this is a sample list, it is not a full list, there is constant change. France and Italy make monthly payments of about 400 euros per person to everybody with haemophilia or hepatitis C.

I think compensation is a recognition of the fact that the treatment in most cases is provided by the governments, and also the unique problems faced by persons with haemophilia who are infected with HIV and hepatitis C -- and there are different problems faced by people with haemophilia who have these viruses than other members of the population.

First of all, people with haemophilia are already coping with one life-long condition and you are now adding to that mix one or two other life-altering conditions which all interact with each other, and the treatment for one could contra-indicate the other. For example, one of the main side effects of treatment for haemophilia C is anaemia. Well, that is exacerbated if you have an underlying bleeding disorder, so it becomes more difficult.

Many person with haemophilia, in addition to being infected with HIV and hepatitis C were also infected with hepatitis B in the past and also in some cases hepatitis A. They have the full spectrum, and you know, concurrent infection with A, B and C can actually cause more liver damage.

Hepatitis C infection in haemophilia tends to have resulted from many exposures to hepatitis C. For example, somebody who is infected through blood transfusion may have received one, two, three or four units of blood, but a person with haemophilia was getting pools of product which were infected. So they were exposed on many occasions to many different genotypes which generally results in higher viral loads, mixed genotypes and a preponderance, unfortunately, of genotype I, which is the most resistant treatment.

In comparison with the Irish cohort of women with anti D, who were perfectly healthy women who received anti D following pregnancy -- and you know, they have looked at the clinical outcome to date in that cohort -- people with haemophilia generally have a worse prognosis. A liver biopsy can be more problematical. A liver biopsy is not something you do without thinking in a person with haemophilia. The side effects of treatment can be exacerbated by the haemophilia and the progression of their hepatitis C can be more (inaudible) HIV co-infection.

It is ironic in one sense that HIV therapy, thankfully, since 1996 and the advent of heart therapy has markedly improved, so the mortality from HIV has decreased and they have survived since 1996. But it is ironic in that situation that their underlying immune disorder means they are more susceptible to a more rapid acceleration of liver damage due to hepatitis C. So there is a difficulty still there. We are actually seeing that in a person who is co-infected with HIV and hepatitis C in general, statistically, their liver disease will progress more rapidly.

So I think hepatitis C is a chronic life-threatening, life-altering condition, as indeed is HIV. And I think in some cases governments may seek to avoid legal responsibility, but they should be forced to acknowledge their moral responsibilities in these areas.

MR MEHAN: Do you have any statistics on remission from hepatitis C?

MR O'MAHONY: Remission? Spontaneous remission or treatment?

MR MEHAN: Treatment or spontaneous.

MR O'MAHONY: If you look at the statistics that are published in terms of hepatitis C they will often talk about 20% of people will spontaneously cure the virus. I think in our case we have seen very few cases of spontaneous remission. I would put it at less than 10%.

In terms of the efficacy of the treatment, the early treatment with Interferon, in our experience, has about a 9% success rate. The treatment with Interferon

Ribavirin had a better success rate, but still not great, and then when they switched to pegylated Interferon Ribavirin the treatment, the success rate is 40% to 80% -- it is 80% with genotype II and III.

The early treatment for hepatitis C in 1994 with Interferon, success rate of about 9%; later treatment with Interferon Ribavirin, a higher rate of success. But it wasn't until the advent of pegylated Interferon Ribavirin that the success rate went up, and the success rate for treatment of genotype II and III is now around 80% on six months' treatment. The success rate for genotype I is about 40% on 12 months' treatment.

Unfortunately, as I said a few moments ago, the vast majority of people with haemophilia have genotype I, which means it is the one that takes 12 months' treatment and it is the lowest success rate. They are the current rates.

If I can go on to just say some remarks about the former involvement of the Haemophilia Society in decision-making, it was actually a question, Dr Jones, you asked earlier: why haemophilia, why not every condition, would this not lead to a bureaucratic nightmare? It is a reasonable question, and I think one that has been to be answered.

I think unlike most medical conditions haemophilia is hereditary, it is life-long. Your mother may have been a carrier. If you have haemophilia your mother may be a carrier, your children can have haemophilia, your daughters can be carriers, your grandchildren can have haemophilia.

In my case, for example, as one example, I had four uncles with haemophilia, three brothers, one of whom survived, and four cousins. So there are almost enough of us to form our own society. So it is going right through the generations, so the level of knowledge about haemophilia grows remarkably in those situations. In fact you are taught, as a person with haemophilia, if you go into a hospital, do not ask the doctor how you should be treated, you tell him what treatment to give you, because you will know a lot more than the average junior hospital doctor, and that is the case.

I accept that if it was not for HIV and hepatitis C there would not be the same imperative. The history has changed not just the clinical history of haemophilia, but it has changed the outlook and the nature of haemophilia societies fundamentally. I think if it wasn't for HIV in 1982 and 1983 that haemophilia societies would have gone along gently with every-improving treatment if HIV and hepatitis C had not come along, and there would not be a compelling case for the formal involvement of the Haemophilia Society.

But I think the case now is utterly compelling because you actually get better decisions made with them in the room, because they actually have more knowledge, and I have seen this in our work at the World Federation of Haemophilia, that the most knowledgeable people I know about blood products, about haemophilia products, are in fact people with haemophilia, who have put a lot of time into this over the years.

I have set out the formal involvement of the Irish Society in relation to decision making on a statutory basis. However, I would like to point out in other countries there is also formal involvement, and in some situations that has occurred directly as a result of inquiries into HIV and hepatitis C.

The United States Senate had an Institute of Medicine inquiry in 1994 at which I gave evidence and, following that, the National Haemophilia Foundation, which is the United States patient organisation, are formally involved in the bleeding disorders advisory board and the Food and Drug Administration drug products advisory committee and in the FDA transmissible spongiform encephalopathy advisory committee -- my apologies for that, just call it TSCAC, it is the variant CJD committee. In Canada --

LORD ARCHER OF SANDWELL: In the United States, is this problem generally addressed at federal level?

MR O'MAHONY: The Americans don't like "national" anything. I spoke at the FDA blood products advisory committee; when I mentioned national tenders I could see the hairs standing on the back of their necks. They generally would have some federal guidelines and federal oversight, but it would be dealt with on a state by state basis. So they would never have a national tender, for example. But they would have state tenders and sometimes conglomerates of hospitals getting together to tender for product.

In Canada, following the Queever Commission of Inquiry, the Canadian Haemophilia Society are formally involved in the Canada expert advisory committee on blood regulation and the tender committee of Canadian blood services, and the Quebec tender committee as well, and on the Canadian Blood Service board of directors, and on the Canadian Blood Services national liaison committee.

In Australia, following the Senate inquiry into the infection of persons with haemophilia, the Haemophilia Foundation of Australia are now involved on the National Blood Authority board and on the National Blood Authority tender evaluation technical committee, and on the National Health and Research Council.

In Japan, following HIV litigation, the Haemophilia Society is now involved in the Ministry for Health and Welfare advisory committee on blood products.

In Thailand, when they did their first tender, their first national tender last year for Factor concentrates, the Haemophilia Society were involved, and I was asked by the Thai Government to attend as an expert adviser to the Society on that occasion.

In Georgia, the Government have established a National --

LORD ARCHER OF SANDWELL: We are talking about Georgia in eastern Europe?

MR O'MAHONY: Yes. This is interesting, because this is a country where they have just started developing haemophilia care in the last three or four years, and they are learning from best practice. They are now seeing best practice means you include the clinicians and the patient organisation in the decision-making process, and in fact the first formal meeting with the deputy minister chairing the meeting is taking place next week, and I am attending the meeting. But it is interesting that they are looking at this now as best practice.

In Russia, the Federal Health Services have signed an agreement with the Haemophilia Society for the setting up of a National Haemophilia Care Programme.

In Brazil, the Haemophilia Society is involved in the national tender technical committee, and that is also the case in Ecuador, in Tunisia and in the Lebanon, so you can see an enormous range of countries, varying from developed to emerging countries, are formally involved in the patient organisation and the decision-making process (inaudible).

There is a recently established clinicians group in Europe, the European Association for Haemophilia and Allied Disorders, which brings together the leading haemophilia clinicians in Europe, where they are going to look at doing joint research on various projects and look at various guidelines for care, and they are drafting European treatment protocols, draft European treatment protocols.

This group includes prominent UK haemophilia treatment clinicians and in their principles of haemophilia care, and I am quoting directly from those principles, they state:

"Clinicians and patient representatives must be part of national and/or regional haemophilia care decision making in partnership with ministers for health and social affairs and those organisations that deliver haemophilia care."

So it is now recognised by the leading clinicians in Europe that you must have the patient organisation represented in the decision-making process.

LORD ARCHER OF SANDWELL: Is this based on the EC?

MR O'MAHONY: It is broader than the EC.

LORD ARCHER OF SANDWELL: It is non-governmental, presumably.

MR O'MAHONY: It is non-governmental, and the clinicians have got together themselves. Now, I think they have already drafted a statement of European haemophilia treatment principles, including the statement I have just made there, and I expect they may get some funding from the EEC to forward that work and to do more work in relation to that. But it would also include some of the countries in eastern Europe which are not currently EC members.

LORD ARCHER OF SANDWELL: I see, thank you.

MR O'MAHONY: If I can conclude by saying that approximately 4,670 person with haemophilia contracted HIV and/or hepatitis C as a result of treatment with contaminated blood or blood products in the UK, and the infection of people in the UK and in other countries, including my own country, is an appalling and unprecedented medical disaster to befall one limited community of people, and

I am aware that the Society had been calling for some years for a formal inquiry, and I would like to congratulate you, Lord Archer, and your team, for setting up this independent inquiry, which I hope will assist the people with haemophilia in getting some answers, and I also I hope will assist them in getting some closure for at least some of these issues.

In my view, a society should be judged not on how it treats the wealthy, the influential or the healthy. It should be judged on how it treats the poor, the ill or the disadvantaged, and many of the thousands of people with haemophilia who have been infected with the HIV and hepatitis C, through the administration of state-provided blood and blood products, have died. Many others are living in poor health, without any guarantee of access to the best available healthcare on an ongoing basis. Without the assurance of the provision of optimum healthcare in the future and with the constant worry of not being able to provide for themselves and their families financially, I strongly endorse the submission from the UK Haemophilia Society in relation to future care, treatment, organisation and provision of financial support.

The UK has long been served by the renowned and well respected UK Haemophilia Centre Doctors organisation, and the United Kingdom also carries out one to three national tenders for the purposes of Factor concentrates on an annual basis.

I would also be of the view that a National Haemophilia Committee should be established in the UK to include representative clinicians from the Haemophilia Society and from the Ministry for Health to allow for formal input by the Haemophilia Society --

LORD ARCHER OF SANDWELL: At the risk of being tiresome, could I interrupt just once more?

MR O'MAHONY: Sure.

LORD ARCHER OF SANDWELL: I was wondering what the system for procurement is here. We have been told that normally Haemophilia Centre directors or hospitals procure -- make their own procurements and deal directly, contractually with the suppliers. But there is such a thing here -- I don't know how you pronounce -- RHD-CDO(?).

MR O'MAHONY: Yes.

LORD ARCHER OF SANDWELL: That makes provision for bulk contracts, does it?

MR O'MAHONY: I think that there was a tender commission here with the Health Procurement Agency, and you have some of the Haemophilia Centre Directors involved. My understanding is that I think in 2003 there was one national tender for England. I think at the current time there are three national tenders. I think Scotland makes its own arrangements, I think the London area makes its own arrangements, I think there is another tender for Wales --

LORD ARCHER OF SANDWELL: I see, so they may form groups for this purpose.

MR O'MAHONY: Yes, but there isn't --

MR MORRISON: It has moved on and changed slightly this year. I think it is a two-stage tender covering England. But the actual tender process would be viewed as non-compliant with best practice in terms of involvement. It has driven out fantastic cost reduction, but the process of doing that has had firms of consultants involved in doing that. I couldn't describe it adequately, but we can arrange to bring that to the table.

LORD ARCHER OF SANDWELL: Again, I would be grateful. It sounds as though it is not very formal. It is a fairly loose agreement to co-operate.

MR O'MAHONY: I think it is pretty -- my understanding is that it is pretty formal, but the involvement of the Haemophilia Society is not formalises, and I think that my understanding in the past here is that they have invited the Haemophilia Society to participate as observers or to be there, when they remember to do so. There is a difference between that and being in the room as of right, a vast difference.

LORD ARCHER OF SANDWELL: Of course.

MR O'MAHONY: And going right back to the mid-1990s, I would often be invited by the Centre (inaudible) to sit with them when they were looking at various products, but that is different to being formally involved as an organisation.

LORD ARCHER OF SANDWELL: Of course.

MR O'MAHONY: And I think it is that formal involvement that is crucially important. First of all, in Ireland it has given the patients tremendous confidence in -- when a product is changed they now say, "Okay, if you agree with this change and the National Haemophilia Director agrees with this, then I am happy if both of you agree, if you are both in the room when the decision is made".

Secondly, the formal involvement, as Roddy, I think, said earlier, means that the haemophilia societies not only have the involvement, but they have -- to get the resources they must put the right people in the room. This is not the sort of thing where you bring in a volunteer for a year. It is a long-term commitment, the person must commit to learning a lot about blood, blood products, recombinant products, technology. So therefore the formal involvement means that you now have the reason for really training people and for doing that, you know. And if it is informal, it doesn't work.

LORD ARCHER OF SANDWELL: Yes.

MR O'MAHONY: As I said, I believe that a National Haemophilia Committee should be established in the UK to include the clinician representative, the Society and the Minister for Health.

I believe the Society should have a formal participation in the tender procurement process.

I am aware that for many people with haemophilia in the UK, and I have spoken to people here, have difficult for paying for and accessing some health services on an ongoing basis, and I would really like to see some provisions similar to those provided in Ireland under the Health Amendment Act legislation, I think that would be very useful in alleviating the financial burden of illness.

I do not believe it is fair that any person with haemophilia who has HIV or hepatitis C through blood or blood product provided by the state, should have to worry about paying for their healthcare for any part of that condition or any condition that they develop.

I would endorse the view that I would like the UK Government to look at the insurance legislation that was passed in the Ireland and look positively at making a similar provision in the UK.

I believe that adequate compensation should be paid to people with haemophilia who have been infected by hepatitis C and HIV, and that this should take account of the pain and suffering they have endured, and continue to endure, the loss of earnings and the loss of their potential, and their current and future requirements in relation to being able to provide for themselves and their families.

I also believe it should not ignore the suffering of partners and of windows of those who have died. I think it is shameful and undignified that many of the people with haemophilia and their families are in poor financial circumstances and they are reliant on discretionary payments or assistance.

I know that the Macfarlane and Skipton funds have done good work and continue to do good work, but I believe that adequate compensation would give the people with haemophilia independence but also dignity. At the moment they are being denied control over their own future, and many of them believe that they are being condemned to a life of means-tested benefits and in fact whereas I know that the Macfarlane fund and the Skipton fund have been very good it is demeaning to have to go back to a trust fund on a constant basis for financial help and assistance. At the very least, people should be offered their dignity and that is not being offered at the moment.

Finally, it is inconceivable to me that the Haemophilia Society in the UK receives so little financial support from the Government and that even this limited financial support is under threat. We have been in the happy position in Ireland that we have not taken any funding from pharmaceutical companies for the past several years, and in fact if we take any funding in the next couple of years it will be to help projects we are doing with haemophilia societies in developing countries. I believe that the Society here in the UK, because it is not getting sufficient Government funding, have to spend an inordinate amount of their time and effort in raising funding, rather than doing the work that they could be doing for people with haemophilia.

I believe it is fundamentally immoral for a government to provide medication which results in the infection of persons with life-threatening viruses and then to abandon their representative organisation, which is the only organisation which is their focus for help and support and assistance, and abandoning them is what they are doing by not providing ongoing reasonable financial resource.

I hope the Inquiry in its report will urge the Government to take action in these areas and a high proportion of the haemophilia population have been directly affected by infection with hepatitis C or HIV in the UK. I think the response to date by the UK Government has been miserly and grudging and I hope, Lord Archer, your Inquiry will be the catalyst which will help to force the Government to respond with compassion and with the necessary measures which they should already have taken. Thank you.

LORD ARCHER OF SANDWELL: Thank you very much, Mr O'Mahony. (Applause). It seems you have a great deal of support for those recommendations.

MR O'MAHONY: I feel very strongly about them.

DR NORMAN JONES: I really would like to thank Mr O'Mahony for an excellent presentation, most helpful. I asked the questions I had as we went along, thank you.

MS JUDITH WILLETTS: Yes, I think I am all right. I just wondered very, very briefly, because I know you have had a long session with us, how has all this changed the community in Ireland, in terms of -- we talked a little, I think, about closure, and we have talked a bit about -- what is the perception now in perhaps how they are being treated and the progress that has been made? Is it a more satisfied community, does it feel it is a community that is very much moving forward because of its involvement and because of its now official voice? I think it might be interesting to get a little bit of a flavour of that.

MR O'MAHONY: I think in some ways a lot of the individuals with HIV and hepatitis C, and particularly parents with children who died, put a lot of faith in the Inquiry, at the end it left a bad taste in their mouth because they didn't get closure, and in fact I think for some of them closure will not be possible. You know, for them justice would be if their child was still alive, and that cannot be remedied. So in that situation you look -- this might provide the answer, this might -- and in some situations closure will never be possible, the wounds will not heal.

But for the majority of people with haemophilia with HIV and hepatitis C in Ireland, I think the work of the Society, the work done before the Inquiry, the Government measures that have been taken, the formal involvement of the Society has been very, very welcome for them. They feel a much stronger sense of empowerment. They feel very much they are now partners in their own care. They are no longer told, "You have hepatitis C, you must take treatment". They are told, "These are the facts, these are the stats", we organise meetings and programmes and they make the decision with the doctor. So it is a consultation process. They are fully informed about the products they are using, and we get very large attendance at meetings if we change a product. We say, "Come along, you are going to inject this product into your child, you should understand what the product is made of", and we get a lot of attendance. There is a strong sense of empowerment, there is a much stronger sense of justice than there was in the past.

The sense of constant worry about having to -- "can I afford to go to the doctor this week, can I afford to take (inaudible)" is gone. The sense of --

LORD ARCHER OF SANDWELL: Could I just -- is there a National Health Service in Ireland?

MR O'MAHONY: There is, but the provision of general practitioner services was always means tested, so you had to pay to go to see a doctor.

So I think their financial worries in terms of getting treatment have disappeared. Their financial concerns in relation to being able to survive, being able to live, have largely dissipated. I think the insurance now, when it rolls on, will be a major benefit to many of them. They really feel -- many of them say "I am coping fine, I am looking at treatment options, but really it would be nice to have insurance so if something happens to me my wife and children are looked after". So it is a much more cohesive community, a much stronger community, a much more empowered community than it was 10 years ago. And I think the same -- you know, if I look back 20 years to 1985, there was anger, there was guilt, there was fear, there was stigma, there was discrimination. That has gone, and the publicity surrounding the Inquiry was hugely beneficial and the media did a superb job covering it, because we had three or four journalists from the national newspapers who covered the entire Inquiry day in, day out, and they did a superb job and really educated the public.

MS JUDITH WILLETTS: So the Irish public is possibly hugely more aware and informed than the UK public.

MR O'MAHONY: Yes, yes.

MS JUDITH WILLETTS: As a result of --

MR O'MAHONY: There is no doubt about that. In fact there was a survey carried out by a marketing company last year -- nothing to do us -- but they used haemophilia as one of the control questions, and they came back to us and said that there was a huge public understanding and awareness of haemophilia in Ireland.

DR NORMAN JONES: I think one thing that came across very clearly in your presentation, which I would totally support, is the very big potential for education in this sort of collaborative way forward that you advocate, and it is very much two way education, mutual.

MR O'MAHONY: Absolutely, and I think if you look at areas like hepatitis C treatment, where, you know, you are asking someone to take a therapy which really destroys their life for a year, with a 40% chance of success, and the success is also predicated on what they do for the year, if they take time off work, if they are able to cope with the side effects. Now, to put somebody into the situation of taking that treatment without proper informed consent and discussion is crazy, and in fact what we have found is even -- and I have spoken to a lot of the people with haemophilia in Ireland with hepatitis C who have taken treatment and interestingly those who have taken treatment who have gone through a year of misery and for whom the treatment has not worked, most of them have felt, "I still don't regret taking it, because I went in with my eyes open, we had a good discussion with the doctor and you take your chance" and I think that informed consent, that ability be involved in the decision-making process about your own health is hugely important for the individual, but also for the society. I think the general rule should be "nothing about us without us". I think if there are going to be decisions made which will affect dramatically the health of the person with haemophilia or the resources available then I think they should be involved in that process, and I think that empowerment is hugely important, and, as I said, I think the Department of Health have recognised that. They can see the clear advantage of having the patients involved.

MS JUDITH WILLETTS: And they have also benefited financially from that involvement.

MR O'MAHONY: Absolutely, and I know that last year when they introduced more stringent requirements in relation to annual funding for charities they asked us if we had any objection to using our budget and our list of programmes, so they could show these to other charities as an example of responsible use of funds. So it has been good from that point of view. Clearly the problems have not gone away, but I think they have been dealt with much more comprehensively.

LORD ARCHER OF SANDWELL: Thank you much, Mr O'Mahony. No doubt we will continue to be in touch.

MR O'MAHONY: Absolutely.

LORD ARCHER OF SANDWELL: As various issues arise.

MR O'MAHONY: I am going to send you the quote from the minister in Parliament, the apology.

LORD ARCHER OF SANDWELL: Thank you.

Are Mr & Mrs Hilary here?

MR MEHAN: They have telephoned to say there has been an unpredictable personal circumstance why they cannot attend.

LORD ARCHER OF SANDWELL: We are dismissed until 19th September.

Could I just ask you, Mr Morrison, you very kindly said that you would talk to us about procurement, or give us something on procurement; could you do that over time, if possible, please, so we can see what the position was at various periods.

MR MORRISON: Yes, of course.

(3.24 pm)

(The hearing adjourned until 19th September 2007)

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