Penrose Inquiry

The following transcript is for Day 31 of the Oral Hearings of The Penrose Inquiry, held on 10th June 2011.

Please note that this session comprised two parts:

The first was an open session, and the transcript is a verbatim account of the proceedings with all supporting documents referred to in the course of evidence available through hyperlinking.

The second was a closed session during which a patient or relative gave evidence anonymously to protect their privacy.

Supporting documents referred to by this anonymised witness during the course of evidence, such as medical records and witness statements, will *not* be hosted on the Inquiry website, in the interests of confidentiality. These supporting documents have been made available on the basis of specific undertakings of confidentiality to the legal representatives of Core Participants and have been considered by Lord Penrose and the Inquiry Team. Except to the extent that they are published by the Inquiry, the evidence given by these witnesses in closed sessions and documents relating to those witnesses are the subject of a Restriction Order made by Lord Penrose under sections 19 & 20 of the Inquiries Act 2005 preventing further disclosure or publication.

Consequently, unlike other transcripts on the Inquiry website, hyperlinking has been disabled for the closed part of the session.

Friday, 10 June 2011

(9.30 am)

PROFESSOR IAN HANN (continued)

Questions by MR GARDINER (continued)

THE CHAIRMAN: Good morning. Yes?

MR GARDINER: Thank you, sir, good morning, Professor Hann. Can you hear us all right?

A. Yes, very well.

Q. Good morning, Professor Hann.

A. Good morning.

Q. The last time you gave evidence to the Inquiry the session was cut off and so I have just one or two further questions to ask you. Before I do that, I would like to clarify certain points of your evidence and I'm going to be referring to the transcript of your evidence, if you have that in front of you. Now, the first thing --

A. Just give me a few seconds.

Q. Sure. (Pause)

A. Right.

Q. Thank you. It's at page 63 I would like you to look at first of all. Line 18, if you can find that. The question is really about --

A. Sorry, page 63 of my evidence?

Q. Page 63 of the transcript, yes. At the bottom of the

page, line 8, where you say:

"Answer: Yes."

Do you have that?

A. Just a moment. (Pause)

Yes.

Q. The context here is results, testing, discussions and so on, and your answer is:

"Answer: I mean, basically, for many years in paediatrics, and certainly before this time, the old idea that you basically gave partial or unworrying information to people had almost entirely gone and certainly had gone in this unit. So if people asked you about things, you answered them honestly. We had a problem, which wasn't entirely resolved, over what we could tell to the children, the so-called Gillick competence was coming through and we game more confident in that respect and then less confident with the pronouncements after Lord Scarman from Brazier and Donaldson and others."

I just want to clarify with you there, when you refer to the Gillick competence, you are referring to the House of Lords case, Gillick v West Norfolk and Wisbech Area Health Authority. Is that right?

A. Yes.

Q. Yes. That was a case that dealt with the prescription

of contraception to children under 16 and it contained an test set out by Lord Scarman, which was called the "Gillick competency test". That's right, isn't it?

A. Correct.

Q. Broadly it said that parental rights to determine treatment terminated when the child could understand fully what the treatment was. Would you agree with that?

A. Yes, able to make up their own mind.

Q. Yes, thank you. Then subsequently there was a case, R v R, where Lord Donaldson seemed to contradict that test. Is that why you are referring to Lord Donaldson there?

A. Yes, I think it made things less clear for us as clinicians.

Q. Am I right in thinking that when you referred to Brazier, you are talking about Margaret Brazier, the professor of law at Manchester University?

A. That's correct, yes.

Q. She introduced further questions about the tests that had been formulated. Is that right?

A. That's correct, yes, and I did know her at the time and she gave us -- basically she sort of put it into a practical form for us, interpreting the medical law, if you like.

Q. Yes. This would have been around about the middle of 1985. Is that right?

A. I thought it was a little earlier than that but I'm not sure.

Q. Yes, thank you. Just to look at how you approached the question of discussing treatment with the children, having considered the advice that you were getting, what was your approach at that time -- I'm talking about 1984 and 1985 -- to the children.

A. Yes, this continued to be a problem in fact. It wasn't just a problem around that time, because obviously we were also looking after a lot of children with leukaemia, bone marrow transplant et cetera, with a high mortality instance and it was particularly difficult in the adolescent age groups and in the more confident children, if you like.

The attitude was always try to take the families with you and to get them to agree what you said to the children, and that they would lead the way in this respect, because obviously our idea wasn't to disenfranchise them as parents, it was to encourage them if possible to adopt an approach which was open with their children as well. Because, as had been shown quite clearly through psychological studies in the past and subsequently, if the child knew what was going on,

there was a great deal less resistance to, for instance, invasive procedures et cetera and less long-term psychological disturbance.

Of course, some parents felt that the least known, the better, and that using words like "leukaemia", "cancer", "HIV", "AIDS" et cetera, was only going to be frightening, would only raise anxiety et cetera. So our attitude was this: in the very young children, those who obviously didn't reach that level of Gillick competence, as it was first described, we basically encouraged the parents and developed literature, in fact, especially in the leukaemia field, for children themselves and for parents to guide them as ways in which they could approach consent and information, then basically left it up to the parents as to what they did. Although clearly we had to repeatedly remind ourselves of what their attitude was so that people didn't speak in ways that disrupted the confidence within the family.

With regard to adolescence, it was obviously a great deal more difficult because if the family chose not to inform an adolescent about what was happening, it made our job difficult and, you know, we, as doctors, nurses, healthcare professionals, do not like prevaricating to people. So it was a difficult situation. There were a few families in which this persisted as an attitude

even for years to come.

I think that's where, legally, the legal information was sometimes not precise enough for our means, understanding.

Q. The Inquiry is particularly interested in the testing for HTLV-III in 1984 and 1985. Could I ask you to think back to how you approached passing on that information, whether it was given directly to the children, whether it was given first to the parents and then the children. What was your approach at that particular time?

A. Well, one thing is for certain, it would never have been first to the children, even if they were 15, 14, whatever, unless they were -- and I don't remember any 18/19 year olds. Obviously, if they were legally in every way adults, it could have been different but I don't think that was the case. So I have already, if you like, admitted that we didn't get pre-test counselling right in the HIV area, we certainly did not and that was shown up in Patricia Hewitt's work subsequently and in the response that at least one parent gave to me, which I have already spoken about.

What we learned in this era -- I have said this already -- is that when you have something that has such a life changing consequence, you have to explain the reasons for the test, explain the possible outcomes with

the possible positivity/negativity and so on and so forth. We didn't do it well. I don't think anybody did actually -- and mea culpa, that was not good and by the time -- and I'm not defending myself here -- we got to the 1990 Hepatitis C episode, some people were still getting it wrong despite all this, but by that time, certainly at Great Ormond Street and Yorkhill, we had fully taken Patricia Hewitt's very good work that, you know, we needed independent counselling, we needed pre-test counselling, we needed, if you like, proper consent not, you know, "Trust us, we will always do the right tests". Obviously we need to do the tests et cetera.

So -- a long-winded answer to your question -- the fact is I don't remember exactly how we approached the pre-test counselling or if in fact we did very much at all to be perfectly frank. The attitude in those days the, blood tests were there, they were taken for hepatitis, we had explained and they knew all about hepatitis and if anyone asked, we would certainly have told them that this testing was carried out, and I do not recall anybody complaining that the tests were done. There was certainly one complaint, which was quite valid, that we had done it and we had told somebody and they didn't really want to know at that stage.

As far as informing people, then informing them, in my view, was when we were sure that the test was correct, even though -- and I think Mark Winter and others have pointed this out -- we did not know a great deal about what the positivity of the test meant at the time. I differed from some other directors in that I believed it was wrong to keep that information from people, even though there was very significant uncertainty about the consequences of the positivity or negativity.

Q. Thank you, Professor Hann. My question is very specific; it's really who was told about the results of these tests? Was it the children on their own, the parents first then the children? I think you have told us that the children certainly wouldn't be told on their own. Can you recall, Professor Hann, what your practice was in terms of did you sit down with the children and the parents to pass on or did you speak to the parents first?

A. To be honest, I don't remember, but in these circumstances I would be very surprised if it were not the case that we spoke to the parents on their own and then would offer -- because this is what we did with leukaemia et cetera. We would say, "Do you want to pass that information on yourself? Would you like us to talk

to them separately or with you?"

That was a policy from the late 1970s onwards in paediatric units. I would be very surprised if we did it in any other way.

Q. So you effectively had a policy in place already about that?

A. Yes, because it was part of a big unit and that was just -- you know, I'm not belittling it, it was one part of a large unit, where there were a lot of very serious illnesses and a passing on of a lot of very serious information, dying children, half the children with leukaemia in that era would have died. So we obviously had to have a policy towards such events. And it wasn't a written policy because obviously it's adapted to the family and the age of the child and all the rest of it.

Q. Yes, I understand. So that would mean that when the results arrived, you wouldn't have to discuss with Dr Pettigrew what your policy was specifically about that particular issue?

A. No, I mean, if obviously she wanted to say, you know, "How do we approach this family with this adolescent who doesn't know what's going on", et cetera, then we would have discussed it, but in the end this is a process of trying to take people with you; it's not just a one-off event.

Q. Thank you.
A. But, yes, he would have obviously been aware of the general ethos.
THE CHAIRMAN: Professor, I'm anxious to know how far the practice you have described would be common among haemophilia directors. You have explained to us that your background in paediatric medicine included a great deal of interest in leukaemia and that's what took you to Stirling, for example. Do you have any sense of whether your practice was particularly shaped by your previous clinical experience and might have been different from another haemophilia directors or would this be common throughout the profession?
A. Please stop me if I'm being too long-winded but I need to explain the background here in order to answer that.

Basically, in this era, it was a period of change in adult medicine in particular. I grew up, if you like -- I had to do a joint training because you couldn't just train in paediatric haematology in those days. So I had to do a lot of adult haematology. And having been a paediatrician and subsequently, I was shocked by the fact that people still spoke to patients, adult patients, in a way which was often concealing the truth, if you like. In other words, "No, you don't have cancer you, have a nasty ulcer that's not getting better".

That was very much the attitude of the time in adult medicine. You would tell the relatives, the wife, the brother, the whatever, what was happening but you know, "Why unnecessarily worry people?"

It was a very, very strong attitude at the time.

Obviously, I didn't work in the adult units in Scotland. I did spend a lot of time in the adult units in the UK and at least one of those, the Royal Free, was very much ahead of the times in this respect, in that they had psychologists, they had counsellors, they were very much open about what they did and they provided counselling, et cetera. But it would not have been uncommon -- and I took part, as you probably saw from some of the minutes of meetings, in meetings where there was a great deal of discussion about, "What's the point of telling people when we don't know what the test is?" And my attitude was: I understand that but I can't see the point in being like that because, apart from anything else, we need those people to know that there is a disorder which can lead to life-threatening pneumonias for instance.

So it isn't a cough that you go to your GP with or put up with or whatever it may be. In order to be able to manage the patients properly -- and I suppose this is part of my defence as to why we went ahead and did

pre-testing without full counselling and consent. We had to know those results. But let me put it this way. There were two camps in the adult field in particular, much less so in paediatrics because it's very much more difficult to keep things from parents than it is from adult patients anyway.

There were two camps with the adults. There was a camp that said, "Let's just do these tests. Let's see how it goes. Let's tell them when it's necessary or we may tell their relatives, and if we are forced to do so, let's tell them. But why worry them unnecessarily when a positive test might become negative, when we don't know how many positives are going to become AIDS, et cetera. Why worry people unnecessarily?" I don't know the proportions but I would say there was a very significant proportion of adult treaters who went down the, "Let's keep it under wraps until we know where we are" sort of thing.

Sorry, very long-winded answer. But I think in paediatrics, it would be highly unlikely that attitude would have existed.

THE CHAIRMAN: Yes. Don't be concerned about making that too long. It's very difficult, looking back, even for you to capture the atmosphere at the time and I have the impression that I really have to know how things were

changing since, as you know, patients and their relatives are commenting adversely on the fact that they discovered later that testing had been carried out.

A. I think, you know, it's one of the regrets I have that we didn't do as well as we could in retrospect, but I just would make one point for the Inquiry: this was a time of great change and HIV was one of the things that had prompted it. It was a time of great change in the attitudes towards consent, towards information giving, towards all sorts of things and HIV was one of the things that changed. It came out of a clear blue sky as a terrible shock and by the late 1980s, things had changed out of all proportion.

THE CHAIRMAN: So one should understand that HIV really provided a focus for change, making --

A. Very much so.

THE CHAIRMAN: Making clinicians think.

A. Not just a change with regard -- it kick-started virology essentially, and so on the clinical/medical side -- I mean, virology/infectious diseases really hadn't developed as a specialty in the UK in a big way but it also changed other things, like it was the first time that we had a disorder really that affected people's lives completely with regard to they couldn't get mortgages, they couldn't get insurance, you know,

their wives might be infected, their families. You know, it changed their lives overnight and that was the first time really that that sort of event had occurred in my medical life.

THE CHAIRMAN: Yes, thank you. Thank you very much.

MR GARDINER: Thank you, sir.

Professor Hann, I would like to move on to the next point of clarification, which is really to do with the dates. Could you have a look at page 67 of the transcript of your evidence. If you look around about line 10, the question is about the initial descriptions of HIV transmission. You say at line 3:

"Answer: My memory is that this became a real issue during 1983. That's my memory."

Then at line 8 you say.

"Answer: I happen to have started on 1 January."

So you started at Yorkhill, 1 January 1983?

A. Yes.

Q. You say:

"It definitely wasn't immediately obvious as a problem but as Dr Forbes said, it sort of hit us later that year that this was going to be a major issue."

So can I just be clear, what you are referring to there is the knowledge at that time that there was a possibility or a good chance that factor concentrates

were transmitting a virus? That's what you are referring to, is it?

A. Yes. A possibility, yes.

Q. A possibility? By that stage there were haemophiliacs who had become infected and died of AIDS?

A. There were reports in early 1983 of, I think it was eight or nine or so haemophiliacs in the United States. The first cases in the UK were later that year.

Q. Yes.

A. I have no reason to doubt the figures in the preliminary report. But I would agree with Dr Forbes. My memory -- and you know, we had lots of meetings and I had lots of meetings with other haemophilia directors at the time -- is that it was not plainly obvious at this time, until later that year -- and I would say the second half of that year -- that this was a blood product transmitted issue in haemophilia.

Q. So from about May 1983?

A. Yes, I would say the latter half but around about that time, yes.

Q. Okay. If we could go to line 20 on that page, you are talking about discussions about this question. You say.

"Answer: We would have said that there had been a few cases described of haemophilia and we didn't know if this was going to be a major problem."

When you say that, are you meaning described of infection in haemophiliacs when you say "of haemophilia"?

A. Sorry, it should say "AIDS and haemophilia".

Q. Yes, thank you. If you could go forward to page 69 and if you look around about line 14, and again you are discussing possible therapies. From line eight you say.

"Answer: So yes, later on we would certainly expect them to have detailed discussions with us about where we go from here, and so if they were newly diagnosed, et cetera, and they were very young, then the use of cryoprecipitate would have been a real possibility that was offered to them and may even have been recommended as the first option in that difficult interim period."

Can I be clear with you, Professor Hann, what is the "difficult interim period"? I presume it's starting in May 1983?

A. Yes, and going through to the period when the virus was found and we found the antibody in a proportion of patients. One of the many problems being, as I quoted from Peter Jones, is that, you know, the incidence of AIDS amongst the haemophilia population was apparently very low, and particularly low in -- and I know you have seen lots of evidence on this -- a country like Germany, using vastly more Factor VIII than we were using.

Q. Yes, but just focusing on the interim period question, you say the other end of the period is when antibodies were found in Scottish patients, I presume you are meaning?
A. Yes, I mean, the test came through in late 1984, I believe, autumn/winter of 1984.
Q. Yes.
A. Then we found the antibodies although we didn't know what that meant either, but at least the extent of the problem was far greater than we had imagined because our patients were asymptomatic.
Q. So the interim period is from about May 1983 to late 1984?
A. Yes.
Q. Yes. Thank you, that's very helpful.

Could I ask you to have a look, please, at another document, to help us with the dates. That's a note of the meeting of haemophilia directors in November 1984. That has a reference SNF0010255.
A. Can you say that number again, please?
Q. Yes, it's SNF0010255. It's a note of the meeting of haemophilia directors and SNBTS representatives on 29 November.
A. I'm sorry I'm going to have to look --
Q. Yes, just take your time, Professor Hann. (Pause)

A. I'm really sorry, I was sent an awful lot yesterday. I have it.

Q. You have it? Thank you.

This is a note of a meeting of the haemophilia directors in November 1984. So I want to try and use this to try and help us with the dates for testing. Do you have that document, Professor Hann?

A. Yes.

Q. Right. If you look at the top of the page, you will see "present: Dr Forbes, Dr Gibson."

A. Yes.

Q. Do you see that, the left-hand column?

A. Yes.

Q. Could you just remind us about Dr Gibson. She worked with you at Yorkhill. That's right, isn't it?

A. Yes, and basically she spent six or nine months as a trainee, as most of them did, and then was appointed -- gosh, I think it was late 1983/early 1984 and it was a proleptic appointment. So she spent between three and six months in Manchester doing some additional training in paediatrics, on the leukaemia solid tumour side to complete her training in that respect.

Q. Yes.

A. When she took up the post, obviously, for the first time

we were two-handed and therefore if I was away or on holiday, for the first time, she was able to stand in. Essentially she was my deputy on this side and she took the lead in solid tumours and leukaemia et cetera, and we worked together as a team otherwise.

Q. When would you have started to work together as a team?

A. It was some time in 1984.

Q. 1984, thank you.

A. I'm not sure. I think -- did she not give you a date in her evidence. July 1984 she says in her evidence.

Q. Thank you.

A. That rings true.

Q. As well as being involved in the solid tumours side, did she also help you with the haemophilia side of things as well?

A. Yes, basically, her training had included a great deal of haemostasis, which is why she took over from me when I left in 1987 or 1988, having trained in McMaster(?), which (inaudible) probably the best centre in the world. So her input would have been obviously when I was away but, as I say, we worked as a team, so we would do alternate nights on-call, alternate weekends and so on. Also she had particular expertise in the laboratory side and helped me to put right a dysfunctional laboratory and also was a very useful opinion actually when it came

to difficult problems with regard to surgeries, management inhibitors, difficult clinical problems like that.

Q. So from July 1984 were you sharing on-call responsibilities equally with Dr Gibson?

A. Yes.

Q. Yes. So she would have occasion to deal with haemophilia patients and she was competent and qualified to do so. Is that correct?

A. She was highly qualified to do so, yes.

Q. She would have dealt with haemophilia patients as well?

A. Yes.

Q. Thank you. Professor Hann, would you usually have been at this meeting?

A. I tried to go to them all but for various reasons I couldn't always, like maybe there was a very sick patients on the ward or whatever it might be. If I didn't, then Dr Gibson would go but that would be rare actually. I usually went.

Q. Yes. Okay, thank you.

THE CHAIRMAN: Professor, looking at this minute, one can see contributions from three different sources of information about tests. In the second paragraph there appears to be a very general reference to the finding of HTLV-III antibodies. Then Dr Ludlam deals with what we

have been calling the "Edinburgh cohort", I think. Then Dr Forbes describes the findings that were subsequently published under the name of Melbye and others, the comparative study, involving Dr Forbes' patients and the Danish patients, and then Dr Gibson reports on the treatment in Yorkhill and says:

"Five out of ten patients were HTLV-III antibody positive."

We know, I think, from general information that the Melbye study was using a French-derived test. It refers to "LAV" in the article. We have some information about Professor Ludlam's patients. How did the results for patients at Yorkhill come to be discovered?

A. To be honest with you, I don't remember. But I'm sure that Dr Pettigrew's memory is correct, in that it came from Dr Follett and in the form of a letter. For some reason I don't remember receiving that letter but the fact was that I did get the results and we communicated them.

When those results had been verified, the problem with the test at the time was not only did we not know about its sensitivity, we also didn't know about its specificity, and also we didn't know what positivity meant. Was it transient, as it is often with other viruses? Was it persistent? What proportion went on to

form AIDS? Et cetera. And there were a number of reports, as you have seen in your Inquiry, of antibodies being positive and then becoming negative. As it turns out, that was a rarity and was almost certainly related to the test producing false positives, as opposed to losing your antibody.

So the answer is that we, like, I think, all other directors, got some results and then required to repeat them and my memory is that the, if you like, gold standard in medical terms test was then repeated with the antibody test, which was the Western blotting which was supposed to be absolutely specific, a molecular test, if you like. So that took some time to come back.

So basically it was a two-step process. The results came through and we tested those who were positive and negative again and also we tested those who hadn't previously been tested over a period of some weeks. And my view was, when we are talking about consent, that there was no point telling people that a test was positive when we didn't even know if that was true. So we got on with doing those repeats as soon as we could and got the results through as soon as we could.

MR GARDINER: Yes, thank you, sir, I would like to follow that up.

Professor Hann, our information is that

in November 1984 there weren't any commercial testing kits available and that at that time testing in Britain was done by Dr Tedder with an experimental kit. We have been advised by Dr Forbes that samples were sent to Dr Melbye in Denmark of his patients. Is it possible that Yorkhill samples were sent to Denmark as well and that's how we have the results?

A. I think that's very unlikely because I don't remember anything about that. I mean, I happen to know Dr Tedder because I have worked in London and I was a UCL person and all the rest of it, and I think that we had organised -- you need to check this because I'm not certain about it -- for him to do the Western blot follow-up and repeat antibody testing some short time later.

As it happened, we were one of the units where I don't think there were any false positives or false negatives. So whatever we got from him in the first instance proved to be correct. I'm almost certain that's true.

Q. Well, leaving aside the type of test that was done, is it possible, Professor Hann, that the results that Dr Gibson is telling the meeting about here are the results of tests that have done by Dr Tedder?

A. Yes, probably.

Q. So it's possible that the initial results at Yorkhill were from Dr Tedder and not from Dr Follett?
A. It's possible but I really cannot remember. I'm sorry, I just don't know.
Q. It's our information that the kinds of tests that you are talking about, the Western blot, were developed some time after this period.
A. If it was developed some time after, it was very close to that period of time.
Q. Okay.
A. It wasn't a year later or something like that. It was, if anything, a few months later. But I could be wrong. We certainly repeated the antibody tests in all patients.
Q. Yes. Thank you. I want to go on to another clarification now. Could you, please, go to page 68.
A. Of ...?
Q. Of your transcript. Do you have that?
A. Not yet no. (Pause)
Yes.
Q. The context here is the possibility of going back to cryoprecipitate treatment from concentrate therapy, and the question is would you have given patients the option to take up a different therapy, for example to go back to cryoprecipitate? You say.

"Answer: Yes, to put it the other way, we would not have resisted that suggestion from them, that it is for certain from our point of view, for those patients who were receiving treatment at the very early stages of their disorder, we offered cryoprecipitate treatment if it was possible logically to give them it, if their veins were adequate et cetera. My memory is -- which may be incorrect, that -- there were some patients, certainly in 1984, who may have reverted to cryoprecipitate treatment for a period of time. That is my memory. I certainly think there were some guidelines coming through -- I can't remember exactly when they came out -- that very young children should be considered for cryoprecipitate treatment and I do believe that we offered that as a possibility."

I just want to clarify: a patient who was on concentrates in late 1983, would you have specifically offered him or his parents the possibility of stopping concentrate therapy and returning to cryo?

A. Yes, I believe that we did.

Q. Okay. It is just in this paragraph you seem to be distinguishing between patients who are in the early stages of their treatment.

A. Yes, I mean, the point here is related, first of all, to reactions, secondly, logistics and thirdly, home

therapy.

As far as home therapy is concerned, it's extremely difficult and unlikely that you can maintain home therapy with cryoprecipitate and so, you know, the lives of these families, as the Haemophilia Society repeatedly made the point during this period, would be changed dramatically if they were to revert to cryoprecipitate treatment, and therefore the majority of families throughout the UK actually chose not to have to go on to cryoprecipitate therapy. Logistically, the second point is that with children with extremely difficult veins, cryoprecipitate could be very difficult indeed to give and therefore there was not much choice.

Thirdly, very young patients were usually managed as hospital-based patients, as opposed to home therapy-based. So you know, they would be using cryoprecipitate in the first instances often. But there were patients also -- sorry, I forgot to say -- who had had severe reactions to cryoprecipitate and who could not tolerate cryoprecipitate, both for logistic reasons and for reasons of reactions, and one of the reasons why a home therapy was largely abandoned in the vast majority of patients in the 1970s, before concentrate became available, was because there were life-threatening episodes of anaphylaxis and reactions

at home in those patients.

So the answer is that I think my memory is, in late 1983 people like Peter Jones and others were -- and may be the UKHCDO in late 1983 -- suggesting that children could be treated with cryoprecipitate and this might become some sort of policy.

There was no written policy that I was aware of and it had to be tailored to the patient and that was the period when I'm almost certain we did change some patients over to cryoprecipitate treatment and continued others for longer than we would have done previously.

Q. So did you then have a policy of speaking to every single patient and offering that possibility?

A. Yes, I mean, basically again these patients were often coming up regularly. We also had instituted a clinic and a parent support group and all of these issues were discussed and also, of course, the Haemophilia Society was putting out information at the time.

So we made every effort to do so. If people fell through the net -- to use a horrible term in this respect -- then I regret it but we certainly made every effort to do so.

Q. Okay, thank you. I would like to move on to the topic of testing that we discussed previously. Could I ask you to have a look at page 73 of the transcript?

A. Yes.
Q. Look at line 13. The question is about your communications with Dr Pettigrew but what I'm interested in is your answer, line 12.

"Answer: We had discussions and had had discussions at national level."

This is about what policy to pursue in terms of advising patients about their results. Can I ask you to have a look at a document which I think you should have a letter from Dr Craske dated October 1984. I can give you the number, SNF0014020.

A. Yes.
Q. Do you have that? Thank you.

You will see that this is a letter from Dr Craske and the heading is:

"Factor IX, batch HL3186. Possible risk of infection with human T cell lymphotrophic virus type 3 with subsequent development of AIDS."

It's advising about a donor to a plasma pool having been diagnosed with AIDS. We don't need to look at it in detail but later on in the letter there is a discussion of the strategies to be pursued in passing over results to patients.

What I'm interested in, Professor Hann, is whether you remember seeing this letter at that time, late 1984?

A. I think so. Certainly the tenor of it rings bells in the memory.

Q. Yes. Well, if we could just have a quick look at it. If you go to page 3, which is 4022.

A. Yes.

Q. In the middle of the page Dr Craske is talking about the follow-up to patients and talks about two alternative strategies. Number 1:

"If the patient has been informed of the risk."

Number 2:

"An alternative strategy would be not to tell the patient."

Then he says at the bottom of that section:

"The ethical problems involved in these two alternative methods of follow-up are discussed in an appendix at the end of this letter."

If we go to the appendix, which is 4024, this is headed "Ethical problems associated with HTLV-III infection in haemophiliacs". Again, he repeats:

"Informing the patient and his family of the risks and then restricted follow-up."

So this is a discussion about what to do with results. At the end he concludes:

"In my view, option 1 is the only one tenable on moral and ethical grounds."

This is advocating informing the patient for various reasons.

Do you remember if this letter that you saw at that time informed the way that you approached this question?

A. I think it was one of many actually. We had lots of discussions about this at the time and this was one of many. I think it helped to crystallise the situation, if you like, in, I think, quite a nice way and I tended to agree with him, whereas quite a few others didn't.

You know, in the end, I think, as a clinician, there is one test above all others and that's a need to know. There are moral, ethical -- you know, you can go round in millions of circles with those discussions -- and legal ones too. But in the end, if you have a disorder which can be transmitted and where people can develop treatable sequelae, then it's not such a major issue in my view. The prion problem that came later was much more difficult -- much, much more difficult, and -- I think, you know, we still go round in ever decreasing circles with that but the fact is that in this circumstance I thought the argument against information was very weak.

Q. But --

A. Other than one point, which was that, you know, there is no point giving inaccurate information, which is just

going to cause anxiety and will do no good whatsoever.

Some people would disagree with that view even but ... You know, for instance -- sorry to go on but if, for instance, we were going round to patients and taking tests again, we would have said the tests are still not accurate, you know, we need to do them again. We don't say, "We have a positive test. We don't know what it means. It could mean nothing at all," et cetera. So we would give partial information, if you like.

Q. But you are saying that there was a section of the medical community that took the opposite view from you?

A. Yes, and it went down these lines but also made the point what treatment is there for this, and the answer is it was beginning to come in the late 1980s and so things changed. And the thing is that ethical questions change over time, but also we knew that there were effective treatments for pneumocystis in particular. You know, we had been treating pneumocystis for many years. So it would be, in my view, wrong not to make people aware that the sequelae of the infection were treatable.

Q. Was your view the prevailing view, would you be able to say, at that time?

A. My view in paediatrics certainly was. In the adult view? I think, probably the majority, but there was

a very significant minority that didn't. I can't even remember who they were exactly but there were adult treaters who were understandably concerned about passing on information that they felt would just be unduly worrying.

Q. Yes. Thank you. In the same vein, could I ask you to have a look at the notes of the haemophilia reference centre directors' meeting from 10 December 1984. That's SNF0013850.

A. Yes, I have it.

Q. Could you have your responses to our questions handy as well, Professor Hann?

A. Yes, document number?

Q. That is PEN0120270.

A. Yes.

Q. Thank you. Just looking at the notes of the haemophilia reference centre directors' meeting, I think you told us that you don't remember seeing this at that time, late 1984?

A. No, I don't.

Q. Yes. Thank you. If we look at your responses, at page 4. That's your response to our questions. Do you have that?

A. Yes.

Q. So the question is a reference to that document, and you

say.

"Answer: I'm not aware --"

A. Sorry, could you tell me the paragraph number?

Q. Sorry, it's 7.1, bottom of page 4.

A. Yes.

Q. "I'm not aware of exactly what was discussed at the reference directors' meeting on 10 December but I was fully aware of the many discussions going on around the UK with regard to the issue of withholding test information. And this is a very important point because it relates to the then very thorny issue of why the testing was done."

And you say:

"There was, in my view and that of many others, an absolute imperative to ensure that we picked up on any other infected batches with prospective testing ..."

And so on. This is a separate issue but just because it's raised there, are you aware whether any investigations were ever done in order to try to determine whether any batches of blood resulted in the infections of these children?

A. My memory is that was carried out but was very difficult to do. It was certainly done in the UK because I had to provide the evidence for Lord Justice Ognall's investigation there and we went through that in detail.

But, of course, the problem is that this was the period prior to Mrs Thatcher's act, basically, the Product Liability Act, and so on, and recording was not perfect, and batch allocation -- in other words, you know, trying to maintain single batches for single patients, et cetera -- was also not being carried out.

I think that Dr Crawford and Dr Mitchell and others attempted to bring that in in Scotland way before the rest of the UK in fact, and I think that began to happen while I was in Scotland. But the fact was, when you looked back, the situation was extremely heterogeneous and therefore trying to allocate anything to anybody was virtually impossible.

Q. So it was difficult to work out which batch might have infected which patient. Is that right?

A. That's right but that's why I said "prospective" here. I believe -- but I can't remember the timing of this -- that an effort was made in Scotland -- and the transfusionists should be able to remember this -- to restrict batches to individuals. That certainly happened to an extent while I was in Scotland and therefore one could begin to say, "Right, this is a Hep C high risk batch," or whatever it may be: Prions, subsequently, and so on.

Q. So you think there was an investigation but it was

inconclusive, for the reasons you have given?

A. I know that there was an intention to do so. I don't recall any outcome from it and I wasn't particularly surprised. That's really all I can say.

Q. Okay, thank you. I would like to move on to something you have touched on already: Confirmatory testing. Could I ask you to go back to the transcript and go to page 73, please? Could I ask you to look at line 20? Do you have that?

A. Yes.

Q. So the context here is analysing the results of the test, and you say:

"What did a test mean? That was the original question. So we had to do several things. First of all we had to confirm that test with the gold standard and the gold standard at that time was Western blotting. So we requested that that be done."

Just to help us understand, could you very quickly explain the difference between the two tests? The first test would be the ELISA test. Is that right?

A. Well, it's an antibody test; I can't remember the details, I'm sorry. I must apologise if I have got the timing of the Western blotting wrong. That's my memory, that it was available shortly thereafter. Basically, the tests that came in immediately were based on the

production of an antibody; in other words, for instance, if you get virus infection, you produce an antibody over a period of time -- like hepatitis or whatever, Hepatitis B, antibody -- and that antibody says you have been exposed to that antigen, the antigen being the virus.

That begs a lot of questions about what that means. Does it mean immunity? In this circumstance it didn't. We didn't really know that -- we certainly didn't at the time. Does it mean that it will go away? What does it mean? It's the body's immune response.

The Western blotting test is a molecular test, not an antibody test, that was looking for the virus itself, or virus products, or whatever. As I say, I must apologise if I have got the timing wrong here. That's my memory and we certainly did do the Western blotting. I thought it was very shortly after this time. I apologise if I'm wrong.

Q. Yes. Well, Professor Hann, we have found a reference to the Western blot testing in America in the MMWR in January 1985 but we don't know whether this testing was available in a laboratory in Glasgow at that time.

A. My memory is that it was available very shortly afterwards. I could easily be wrong, but Dr Tedder and Dr Follett will be able to answer those questions.

Q. Yes. I'm glad you have mentioned Dr Follett because, since you were last here, we have communicated with him and unfortunately he hasn't been able to help very much. Perhaps we could just have a quick look at his statement, which is PEN0120800. I'm not sure if you have got that, Professor Hann, but don't worry, I'll read it out to you.

A. I don't.

Q. The context here is that you can't remember whether it was you or Dr Follett who initiated the testing on stored samples. That's right, isn't it?

A. Yes, that's right.

Q. Now, Dr Follett has written back. The Inquiry received his letter on 27 May. What he says is:

"Thank you for your letter regarding the Penrose Inquiry. I am afraid I'm not going to be of much help to you. In the middle of September I will be 76 and I have noticed recently that my memory of past events and even recent events is poor. According to your letter, these tests were carried out over 25 years ago and as such I cannot recall any detail in this regard."

Sir, we have followed that --

A. I want to be completely honest here. My initial response was that I didn't initiate this testing but I

can't be sure and I'm quite prepared to accept the possibility.

Q. Yes. If we just look at another bit of page -- I'm sorry, could you just repeat what you said, Professor Hann? We didn't quite catch it.

A. Yes, my initial response was going to be, when I received this, that I did not initiate this testing, that I got the results, that I probably knew that it was happening but I didn't sort of say, "Please test all of this". But I can't be sure of that. I am perfectly prepared to accept the view that I initiated this testing, although I do not remember doing so.

Q. Yes.

THE CHAIRMAN: I thought the word was "responsibility".

MR GARDINER: It was "responsibility" -- we wanted to clarify what you meant.

THE CHAIRMAN: It would be quite difficult for Professor Hann to reconstruct it.

A. Responsibility for your patients and for what happens to them, and if it was done without my knowledge then I should have objected and made a strong representation and so on and so forth. So I'm not going to devolve myself from the responsibility. My best memory was that it wasn't me that initiated testing but ...

Q. Could it have been another doctor other than yourself

or --

A. Not in the hospital, no. It could have come from the Blood Transfusion Service. It could have come from virology. I don't know. I suppose it's most likely that it came from me, I suppose, is the most likely, although that isn't my memory.

Q. Yes, and certainly looking again at page 73, if you could go back up the page to line 7, you are saying there that, although you can't quite remember how testing was initiated, you remember receiving the results?

A. I remember that I had received the results. I don't remember the letter that Dr Pettigrew refers to.

Q. Yes. What you have told us is that, before you would go back to the patients or speak to the patients, you would want to do a confirmatory test first?

A. Yes, absolutely.

Q. So the stage at which you are discussing the results with Dr Pettigrew, is that after the confirmatory test?

A. No, we would have discussed them as soon as they came through and talked about the state of knowledge at the time -- which she was very well aware of anyway, through her contacts with the adult unit and so on -- and how we approached this and what tests needed to be done and the reliability of such tests.

As it turned out, we were rather fortunate and we weren't one of the units that had false positives, as far as I remember. But it was absolutely imperative because there were false positives coming through that we had a repeat and that the repeat was done as soon as was feasible, although obviously there was no medical emergency because the patients were asymptomatic.

Q. Yes. The reason I'm asking is that if you have to do confirmatory tests, that's going to extend the process by some time.

A. Yes.

Q. How much longer is it going --

A. I would say it was weeks, it wasn't a larger number of months.

Q. So when you first speak to Dr Pettigrew, there is still a further few weeks of confirmatory testing that needs to be done?

A. Yes.

Q. Yes. The confirmatory testing, would that come through as a batch or patient by patient?

A. I don't know is the answer, because basically the way that virology works is that tests are batched because it's much more efficient, cost-efficient and actually safer to do a series together with internal controls et cetera, et cetera. So I would guess that over a period,

there would be a batching of the results in the laboratory, as we sent them in along with the other units throughout Scotland and the UK.

Q. Yes.

A. Then we would get the results of those tests within a relatively short period of time.

Q. Tell me if I'm wrong, Professor Hann, but I'm getting the impression that there wasn't a point where you sat down with Dr Pettigrew and divided responsibility for who would tell which patient about the results. Is that right?

A. No -- well, yes. Basically, those results would come through as we did the clinics together, as we did day care together, et cetera, and as she was available, or I was available, or, for instance, if she had known a family for a very long time, it was often better for her with the haemophilia sister and then, as we developed counselling services, the arrangements thereafter.

Q. Yes.

A. So it was on a patient by patient basis.

Q. Yes.

A. The majority would probably have been through Dr Pettigrew.

Q. Yes. I mean, was there anything potential --

A. Initially. Sorry, I mean initially.
Q. Was there any potential, Professor Hann, for a patient to get missed because of confusion between who was telling which patient?
A. I think it was too serious a problem, too much in our minds, at forefront of hour minds. It wasn't a vast number of patients. I mean, it was of the order of ten. We knew who they were exactly and we had to devise all sorts of -- subsequently -- ways of dealing with those patients with regard to those samples et cetera.

You know, there was a massive amount of hoo-ha as to how the sampling from those patients was managed in the laboratory, how those patients could be managed on the ward and in day care, et cetera. So there was absolutely at the forefront of our mind.

Q. Yes. Thank you.

I would like to move on to another topic now. The last time you were here, and also this morning on several occasions, you have referred to, I think, Patricia Hewitt and I think you mean Patricia Wilkie. Is that right?

A. I'm sorry. There is a Patricia Hewitt who works in the blood transfusion -- sorry, senility.
Q. No problem. Just very quickly, Professor Hann, the Inquiry is going to hear from Patricia Hewitt -- Wilkie.

A. It so happens there is a Patricia Hewitt who is a blood transfusion/hepatitis/HIV person who is very well-known to us all.

Q. The Inquiry is not going to hear from Patricia Hewitt. I'm sorry, it's Dr Patricia Wilkie that the Inquiry is going to hear from. Could you tell us briefly what your involvement with her was?

A. Yes, I don't want to take any credit for this -- or very little. This was something that was set up, I believe, by Charles Forbes and Professor Lowe with the support of a research grant from the Haemophilia Society, and basically it was part of a two-pronged response to the fact that we are responsible doctors and we have realised that first of all this was a new problem that we wanted to deal with better if it ever happened again, and secondly, because there had been instances, certainly in my own practice, where I wasn't happy that we had done it as well as we possibly could.

We basically had a two-pronged approach to this. In the children Dr Fiona Logan, whom I have already referred to, carried out a study in the families and the children to see the effect that this had had upon them and how we dealt with it et cetera, but mainly are they growing up in an acceptable manner.

Secondly, Dr Wilkie did a very good thesis with the

department of psychiatry. And I would just mention that Professor Ivana Markova in Stirling, whom I had had many contacts with, a world renowned expert in the area of psychology and of the effects of haemophilia on persons and families with haemophilia, basically showed -- one thing that we weren't really expecting -- that you needed independent counselling in this process subsequently, something that I and the people in Scotland took on board very much when Hepatitis C came along. Ie a counsellor not wearing more than one hat, as I think she put it. And obviously described what we were seeing in a way, which I suppose we already knew, which was the Sword of Damocles-type of problem that these families were having to face, and I suppose none of us could have failed to realise the terrible damage that that did.

But I also took from that -- and I think others did -- the fact that we didn't get the right approach when it came to pre-test counselling, test counselling, post-test counselling. I think we had the post-test counselling pretty well organised eventually, when resources were eventually allocated, and I think we got the test counselling itself part right, and I think we got the pre-test counselling not very right at all.

Q. Just for information, sir, that research paper is in

court book at PEN0120998.

THE CHAIRMAN: Thank you.

MR GARDINER: Just talking about what you got right and didn't get right, Professor Hann, would you accept that the way in which news is passed over, news like this news of results, is something that is important for a clinician?

A. Yes. It's vital. It changes everything. Because not only does it affect the way that the families can deal with this but it also affects your relationship with that family and the hospital's relationship with that family and taking them with you. I mean, the fact is I grew up in an era where people had ultimate trust and you know, that was unhealthy.

We were coming into an era -- this was, if you like, a phased-in era -- of a time when people realised that we often did get it wrong and being honest about that and open about it was far better, but what we hadn't got right by this time was the approach to counselling.

I will just give you one example of that. In the latter part of my training in Manchester, the department of psychiatry there showed that the interactive skills of doctors was severely inferior to that of nurses, something that perhaps a lot of people realised, but that led -- and I have seen the ethics information that

you received from -- I can't remember the name now -- Dr Nathanson -- about the training that doctors get now, but that again was something that came out of the HIV era and made us realise that we weren't doing it ideally and weren't always placing ourselves in the situation where we were giving information in the best possible circumstances.

We had difficulties of resources, both resources of space and time and of personnel, although we made huge efforts to get that right and that certainly is the case. We didn't always do it ideally and I would just make one final point. Passing on information -- and we all knew this at the time and subsequently -- to families about children at an initial interview is not actually the most important aspect of passing on information because it has been very clearly shown that families don't take in a great deal of information immediately you hit them with it.

We, in other areas of paediatrics, especially the oncology transplant side, had being very used to the fact that you are pass on a certain amount of information, you ask what further information is required but it is the follow-up and the repetition of what you say that's very important.

So, yes, I'm sorry, another too long-winded answer,

but basically, the initial impression is very important. We didn't always get it right. The follow-up is vital and we put a huge amount of effort into getting more resources, and Anna, the haemophilia sister, and subsequently the social worker and counsellors that eventually came on board, followed that up and provided the information, as did the Haemophilia Society, et cetera.

Sorry, finally, there is another forum for information, which is the support groups that we set up for the first time. So it wasn't that we weren't interested in doing this right, we just didn't have it as ideally, optimally at the time.

Q. So you accept that you didn't get the communication of these results right at that time?

A. Not always. But even now it's impossible to -- in every circumstance -- get every family's needs. As I have said, there was one thing that sticks in my mind very much, and I have said it before, the family who hadn't realised that testing was underway, that was informed and then was very angry about the fact that they had been informed because they didn't want to know. That's one circumstance that you have to be able to deal with but it's a very heterogeneous situation and you can only deal with this by an approach that doesn't just rely on,

you know, you come in and out of the doctor's office.

Q. I want to come to that in a minute but just before we do, do you have any personal experience of patients not taking in this kind of news?

A. I would be almost certain that I would be correct in saying that 100 per cent of people do not fully take in this type of news first time around, no matter how clever they are, how scientific they are or whatever. And that is an everyday job of somebody, for instance, who has to go and tell a family that their child has leukaemia, that they have a chance of dying et cetera, et cetera.

It's a matter of judgment how much you can say to people at any one time and how much you have to come back on a daily basis, and that's why the social workers and people like that, who can come back and spend literally hours a day talking to people, are so vital and we had not fully developed that type of role at the time.

Q. I think you described it before as a process?

A. Yes.

Q. So were you meaning it's not just the first meeting, when the news is given; it's subsequent meetings that are important as well?

A. You are right that the first meeting is important

because, you know, you have to generate the view that they have the ability to be, to a certain extent, in charge of the situation, not disenfranchised, able to ask, encouraged to ask et cetera, and told how to ask. Nowadays, a lot of time is spent saying, "Right, if you want to go to the Internet and all the rest of it, this is how you do it". Things change and that's how it happens nowadays.

They may want to talk to parent support groups, for instance, they may want to talk to the Haemophilia Society, which isn't exactly a parent support group and so on. So it's a process. The process has to be followed through but some families choose not to join the Haemophilia Society, not to join support groups, et cetera, and those in some ways are the ones who can fall through the net.

Q. Yes.

THE CHAIRMAN: Mr Gardiner, are we going to have a break?

MR GARDINER: I think we should, my Lord.

THE CHAIRMAN: Yes. I'm just concerned about the technology and --

MR GARDINER: I understand that we have the booking until about 1 o'clock. So I think we have time for a break.

THE CHAIRMAN: Yes. Professor, I think we will have a short break now. The stenographer can't keep up indefinitely

and some of us have the sort of problems you referred to earlier with growing age and need a break for other reasons.

A. Can I ask, am I speaking too fast?

THE CHAIRMAN: It's not too fast, I think the stenographer might like you to speak up a little bit.

A. We can turn the volume up. How long is the break?

THE CHAIRMAN: I usually say ten minutes but my capacity for imposing discipline is strictly limited.

A. Thank you.

(11.00 am)

(Short break)

(11.20 am)

MR GARDINER: Professor Hann, before the break you were telling us about a family who were unhappy about the results being given to them and I think you deal with that at page 5, paragraph 7.45.

A. Yes.

Q. You say:

"I can remember occasions ..."

Let's just get that. It's page 5 of PEN0120270. So paragraph 7.5:

"I can remember occasions when attempts to breach that confidentiality ..."

This is about the results:

"... were made and we all fought very hard to block that activity, with complete success as far as I know. I'm aware that we did not manage this as well as we should have done ..."

And you have dealt with that:

"I would imagine that with time they would be aware that the stance with regard to a child was untenable in the longer term."

Then you go on to talk about examples of attempts to breach confidentiality. This is in 7.6:

"I had contact from dentists and other healthcare professionals wanting to know a patient's HIV status. I always refused to disclose this. There was a great deal of uncertainty with regard to the patient's infectivity of others and I recall that some children in Scotland were unable to attend school because of actions of other parents. I believe that there were contacts from teachers, dentists and possibly GPs but I have no detailed recollection apart from one major incident ..."

Over the page you talk about the major incident. Could you just tell us again, in your own words, what happened with this major incident that you are referring to?

A. It was major to me but did not lead to any major consequences, hopefully. Basically, I was contacted by

a senior person, asking for the names of persons with haemophilia who were HIV positive in a particular area of Scotland. I can't remember exactly where. And I said, "Well, why do you want to know that?" and the answer was, "So that I can inform the dentist so that they can get special precautions put in place because there is a risk that they will develop AIDS."

I said, "Well, what else?" and he said, "Well, I'm going to let the GPs probably know and we will perhaps have to have special arrangements in those surgeries for them to be dealt with, et cetera."

And my response was twofold. Could I just make the point, actually, personally this is just yet another example where we didn't have guidelines in place for anybody in a timely manner anywhere in the UK actually at this time and we were really struggling.

So I mean, basically what I said was, "Look, as far as we can tell at this moment in time, this is quite a fragile virus, you should always have procedures in place -- antisepsis et cetera -- which deals with Hepatitis B. The information we have at the moment, albeit limited, is that that should be adequate, and I'm not going to give you those names because what you have told me is what I don't want to happen because these people are already becoming pariahs", and, you know,

just being a person at that time with haemophilia meant that you could easily be labelled with the "gay plague" as it was often known.

So the outcome of that was that I was told that I had to tell him and I said I wasn't going to, and I then received a contact from Dr McIntyre, either at a Home and Health Department meeting or by telephone, I can't remember which, during which he wanted to know why I had been so rude to the doctor and that he had to support him in his public health role. I said that this is not a communicable disease in the legal or sense. I was under no obligation to go outside my own medical ethics and that I thought that there was a level of ignorance here which needed to be dealt with.

Dr McIntyre accepted that but had understood that I was refusing to give any epidemiological information, which was required in Scotland at the time in order to provide resources, and I said that that was fine by me so long as it was completely anonymous, it was numbers only, nothing else, and was related to large areas so that people could not be identified -- you know, you are a haemophiliac in a small town, et cetera. He said, "Fine, that's all I was really wanting to get out of you", and we left it at that. And actually I don't think they even followed that up, but it was one of many

contacts at the time, and one of the areas that was most difficult was trying to get things done in the laboratory in the hospital with people demanding containment facilities that were way beyond what was necessary, and it was a very difficult time because, despite the fact that the hospital gave us some money to improve those facilities, we still couldn't always get the tasks done in a timely manner.

Q. Yes. So Dr McIntyre would be in the chief medical officer's office. Would he be a principal medical officer perhaps?

A. Probably, something of that nature.

Q. Thank you.

A. I have to say he was very supportive in the end when he fully understood the situation.

Q. Yes. Thank you. Just on that question of confidentiality, when Dr Pettigrew gave evidence to the Inquiry, she said, when she was talking about keeping records -- and if we could maybe look at page 58 of the transcript for Dr Pettigrew's evidence. I'll read it out for you Professor Hann, if you don't have it. If we go down to line 23. The context here is that Dr Pettigrew said that there was a reluctance to write to the parents of patients about the results, even to get them in for a meeting, because of confidentiality.

So the question to Dr Pettigrew was.

"Question: So was there a concern that committing it to paper would --

"Answer: Yes, in fact I don't even think the results were initially entered into the case notes."

So she told us that she didn't think that the initial results of a positive antibody test were entered into the case notes. Does that accord with your memory, Professor Hann?

A. We had to be very careful indeed what we put into any letter with anyone. I can't remember exactly what we told general practitioners even but the fact was that general practitioners were rarely involved in the management of these patients, and for those who were positive, basically they used us as their general practice, and many of them, most of them, as their general dental practice.

The hospital was wonderful in taking all of that on for these people until it was possible to be sure that the information that got out was treated with the degree of confidentiality that was necessary. You cannot be 100 per cent confidential about someone.

We certainly wouldn't have entered anything into the case notes when we first got the results, when the results were verified, and after a period of time we

would have written to the general practitioners to say that the retrovirus testing was positive and, you know, it would have been "strictly private and confidential" and "for your eyes only", and all that sort of thing, so that it wasn't opened by the practice nurse, et cetera, or secretary anyway.

So, yes, initially we didn't enter everything into the case notes and we had to deal with every problem on an ad hoc basis as it came up until people's minds were turned on to the fact that these people could be treated as normal, essentially, or with the same precautions as if they were, you know, possibly hepatitis positive.

Q. Yes. So it is possible that the records of the results of the tests were kept separately from the main records. Is that right?

A. Initially, yes.

Q. How long would that have been for?

A. It would have been for a few months during the initial period when we were trying to get all the systems set up in the hospital to deal with this. The parents -- we certainly wouldn't have put it into the notes until they had been informed so that they knew what contacts they could make, who would be looking after them and they could get their dental care et cetera, et cetera.

Q. What happened to those records subsequently?

A. The case notes?
Q. The case notes that were kept separate.
A. Oh, no, we didn't keep separate case notes. That was never the case. That's only ever done for psychiatric patients, and I didn't look after psychiatric. But basically we knew the names of the patients and I would have a list and Anna would have a list and the haemophilia sister would have a list, and that would be it.
Q. So at some point, would this information find its way into the case notes some months later?
A. Yes, and there was a period of time, even when I was at Great Ormond Street, where, you know, do you have a specific means of identifying these case note? What do you call the clinic that these patients come to? Et cetera, et cetera. It wasn't so much of a problem here actually because there were fewer numbers but, for instance, we had to call the clinic at Great Ormond Street, the "ABC" or the "long-term follow-up haemophilia clinic" or something like that. There were a lot of euphemisms in the early days.

The fact was that none of these patients were symptomatic at the time and there was no overriding need for other people who were involved to know about the positivity unless there were procedures being carried

out or whatever. And then the families would know to contact us or for us to be involved, and I don't recall that it was ever a problem.

Q. Yes, thank you.

A. But we didn't keep separate case notes, we just had a list.

Q. I understand. Just to move back to something that you mentioned before, and I would like to try and deal with this quite quickly.

In paragraph 7.5 of your responses on page 5, you tell us that you remember one family initially feeling that they should not have been told the results, and you mentioned that before the break. What was the nature of the complaint from the family?

A. The nature of the complaint basically relates to the problem here in that, "You have told us something now that is going to be the sword of Damocles over our head. You can't tell us when the outcome is. There is no treatment for it I. Would rather not have known."

Q. Yes. So if --

A. How do you approach that sort of problem? I mean, I suppose with pre-test counselling nowadays you would say, you know, "These are the potential outcomes. Do you want to know or not?" or whatever. This is what we learnt.

Q. But you couldn't do that in this case because the test had already been carried out?
A. Yes.
Q. That's right, isn't it?
A. Exactly but also, you know, the fact is we did have a need to know that the patients were positive and the families did eventually.
Q. Yes. Thank you.

I would just like to move on to another separate question, which is to do with a meeting that was held in December of 1984 in Edinburgh. This isn't in your responses but if you could just try to remember. Were you aware in 1984 of a meeting which Professor Forbes attended, when haemophiliacs were told that at least some of them had been infected with the virus?
A. No. The only recollection I have is that there was a meeting set up between Glasgow and Edinburgh essentially, where I know that Dr Pettigrew was aware of it, I believe, which was supposed to be for support -- it was like setting up a support group, if you like. There was no question that information about diagnosis in the children's group would be passed on in a group of people in that manner.
Q. Yes. So you had no knowledge, in that case, of this meeting in December 1984?

A. I have a recollection that a meeting was set up for parents between Edinburgh and Glasgow, where families attended and -- I mean, it was an open invitation as far as I know, but my recollection of it is very vague, I am afraid. We had our own groups. So I doubt that any of ours attended but they may have done.

Q. Whereabouts was the meeting that you remember? Where did it take place?

A. We had regular meetings, parent support meetings, which were held, as far as I remember, within the hospital. There were obviously of course Haemophilia Society meetings, et cetera, and they were doing their own thing, if you like, but as there was a need for medical input and nursing input, and I had been used to this being set up in London in the couple of years before I took up the post and found it very useful, and actually became even more useful with time. Starting groups of parents with leukaemia, whose children had died. That was a paradigm, if you like, and then shortly after I started at Yorkhill we started up parents' groups. And I believe one of those was more HIV/hepatitis focused and the other was just general information.

Q. Professor Hann, we are beginning to run out of time a bit so I would like to move this on. I'm asking you

specifically about a meeting in Edinburgh in December 1984, when a group of haemophiliacs were advised by doctors that some of them had been infected with the virus. Do you have any personal recollection of that meeting from that time?

A. No.

Q. No? So would I be correct in surmising that you don't remember being asked to write to any of the parents of your patients about such a meeting?

A. I do not remember that at all.

Q. Just on that question, doing the best you can, when do you think that you became aware that Scottish haemophiliacs had become infected?

A. It was I suppose when the letter from Dr Follett -- I don't have that letter so ... it's round about very late 1984/very late 1985.

Q. Thank you. A general question: would you have considered it appropriate for information about children's results to be communicated at an open meeting at Edinburgh Royal Infirmary?

A. It would be completely inappropriate.

Q. Even on an anonymised basis, without naming the children, simply advising that some had been infected?

A. I think if you are talking in general terms about, "There are, you know, X number, per cent, et cetera,"

that's the type of information that families were requesting, and if you are talking about HIV in general or hepatitis in general or whatever, then people like figures and the levels of risk to be discussed.

Q. Yes. Thank you.

A. But you don't say, "John has got it," so and so has got it, whatever. That's a purely individual matter.

Q. Professor Forbes has told us that he attended this meeting in December 1984. Can I ask you just a general question: what were your communications like with Professor Forbes at that time? Did you have weekly meetings, monthly meetings? How did you pass on information?

A. I mean, basically, if you like, the modern term is "translational care" or "transitional care"; in other words, who provides the interface between the children, adolescents, et cetera, as they go to the adult unit, and that was provided by Dr Pettigrew who worked at the Royal Infirmary and knew them very well. My main liaison was Gordon Lowe, in fact. We had actually regular meetings with him. I would see him probably once a month. Anna would see him more frequently than that, every couple of weeks.

Q. Thank you.

A. Eventually we set up a clinic there for transitional

care of patients and patients who have just transferred.

Q. Yes, thank you.

Professor Hann, that concludes my questions about the B5 area. I have one question to ask you which is on the B2 area and it's just to clarify something that you mentioned in your statement to us. So this is Professor Ian Hann's statement to Penrose Inquiry dated 13 September 2010, and it's PEN0150370.

A. Yes.

Q. Could we go to page 0374, which is page 5 on the paper copy under the heading "Lessons to be learned". In the third paragraph you say:

"Much has been learned from this period. We now have recombinant prophylaxis and haemophiliacs are growing up normally as Dr Peter Jones had jumped the gun and said in the early 1980s."

We just want to try to make sure that we understand what you are saying there about Dr Jones. Do you mean that Dr Jones regarded that the problem of haemophilia had been solved when it hadn't really been solved at that stage, that perhaps he went too far too fast?

A. I think it just emphasises the fact that this came out of a clear blue sky. I'm talking about the era before we knew anything at all about HIV/AIDS or any of the subsequent problems. He basically gave a number of

interviews, which were very understandable and his unit had led the way in many respects in Newcastle, and basically he talked about the fact that all the children were going on to home treatment, et cetera, et cetera, and that they could enjoy a normal lifespan for the first time.

You had to remember that when I was growing up and when he was growing up, persons with haemophilia -- as I should be saying, not haemophiliacs, I apologise -- had a very short lifespan and to meet a person with haemophilia over the age of 50 when I was doing my training was very unusual and that's the point he was making, and unfortunately this came and hit us like a sledgehammer.

Q. Thank you. Thank you very much, Professor Hann.

No more questions, sir.

THE CHAIRMAN: Mr Di Rollo, is this a matter that you have delegated to Mr Dawson?

MR DI ROLLO: Yes, it is.

THE CHAIRMAN: Mr Dawson?

Questions by MR DAWSON

MR DAWSON: You haven't given evidence so far in this Inquiry on what the Inquiry has described as topics B2 and B5, and we have heard mostly about the latter of those this morning. I'm going to ask you some questions

about both of those topics and I'm going to start with the B2 topic on which you have just been asked a single question at the end of your evidence this morning.

Could we, please, have up on the screen Professor Hann's CV, which is WIT0030296, and in particular page 3.

You have given some evidence already, professor, about your medical training and you can see there your various training from house surgeon in St Barts and training in various paediatric posts down to the bottom of that page, where we see registrar in paediatrics, Alder Hey.

Could we just skip over to the next page, please? We see there reference to the Royal Manchester hospital. I'm particularly interested in the fact that at entry 10 there, that appears to be the first reference to "haematology". That's your employment at Great Ormond Street between 1978 and 1980. I just wanted to ask you whether that was your first experience in the haematology field or whether your previous posts had involved haematology responsibilities as well.

A. Basically, if you go back to number 3, Professor Sir David Weatherall was and still is a very famous haematologist. That job was mainly haematology. That's number 3. The next job: Dr Martin was

a paediatric haematologist and the heart of that job was haematology. The next job, number 5, Dr DIK Evans was a haematologist and a haemophilia specialist and became chairman of the medical advisory panel of the Haemophilia Society. And neonates and so on.

Number 8, registrar in paediatrics, is again paediatric haematology for half the time. Number 9 is haematology again. Dr Morris Jones was a clinical haematologist and Dr Evans, the haemophilia doctor. Then doctor and subsequently Professor Chessells and Professor Hardisty were the haematologists at Great Ormond Street and so on.

Q. If I can just interject there because I am going to ask you a question about number 11, which you have reached. That was your time working at the Royal Free and I think already you have made some reference to having worked with Dr Kernoff. That was at that time, is that correct? -- between 1980 and 1982?

A. Yes, Dr Kernoff and Dr Tuddenham were the haemophilia centre directors at that time.

Q. In one of your statements you refer to Dr Kernoff as having been a practitioner who led the way in managing patients in the safest ways. What was it that he did at that time to improve safety for patients?

A. Several things. First of all, on the, if you like

holistic side, he appointed, to my knowledge, the first haemophilia counsellor and set up a patient counselling group, support groups, et cetera. And I think basically that was very new at the time.

Secondly, the Royal Free at that time, with Dame Sheila Sherlock, was probably the leading hepatitis service in the world, and the first descriptions of non-A non-B hepatitis et cetera, were all carried out there, and he and Dr Tuddenham were then working on finding -- and in fact did find -- the gene for Factor VIII which has revolutionised things.

This was a world shattering event, Professor Tuddenham discovered that gene. Also they spent a great deal of time trying to address what we thought was one of the problems -- although not, we thought at the time, a severe one, which was non-A non-B hepatitis -- through the development of heat treatments. Specifically their main interest was finding the gene for Factor VIII and developing recombinant safe Factor VIII and IX blood products, but Factor VIII was what they did.

Q. Would it be accurate to say that your time working with these doctors at the Royal Free, in particular Dr Kernoff, had a significant influence over your attitude towards treatment of haemophiliac patients?

A. Yes, very much so.
Q. What was Dr Kernoff's attitude towards the use of factor concentrates in the treatment of patients?
A. I think the best way to describe this was -- I mean, he published widely in the area and in fact 1985 showed that there was a high risk of non-A non-B hepatitis, whether you were treated with NHS concentrates or commercial from the USA. At the time that I was leaving the Royal Free and coming to Glasgow, we had had a series of presentations from Dame Sheila Sherlock herself and from the Oxford group and from the Sydney group, Rickard, Fletcher -- these are all things your preliminary Inquiry very well summarised -- basically showing that patients treated on concentrates had a virtually 100 per cent or 100 per cent risk of non-A non-B hepatitis, whether or not they received commercial or NHS concentrates. And -- somewhat depressing -- that was the Oxford Fletcher study and then the rather depressing study from Sydney from Rickard, showing that even if you adopted what was thought to be the least worst practice at the time -- which was single donor, unpaid donor, cryoprecipitate -- then you still had more than a quarter risk of developing non-A non-B hepatitis. And in fact there were very, very few units in the world, including in Scotland, that could achieve that

approach. That was a study in which you only had 250 haemophiliacs.

So basically, what I learnt at that time was that whatever you used was likely to be problematic from the hepatitis risk, which was all we knew about at the time, and that also, one other point -- sorry, I'm being too long-winded -- but one other point was there was a huge problem with lack of self-sufficiency, that it would be better if the UK were self-sufficient and that there was a theoretical reduction in risk if that had been achieved.

Therefore, my attitude was go with NHS concentrate if you possibly could.

Q. What was the prevalent attitude at that time towards prophylactic treatment with factor concentrates?

A. It was very, very sceptical for a series of reasons, first of all because it wasn't feasible in most places and because, sadly -- and I was culpable to some extent in this respect -- people didn't believe the fantastic results that were beginning to come out of Sweden at the time from Inga Marie Nilsson and others. And in fact it took years after this, probably until nearly 1990 or thereafter, for people to at last accept that prophylaxis worked, and in fact Dr Willoughby was ahead of his time in this respect, and all I can say in my own

defence was that we at Great Ormond Street were the first unit to get everybody on to recombinant prophylaxis in around about 1990.

So, no, there was a great deal of scepticism, both from the logistic point of view -- the belief that it really worked point of view -- and the supply point of view.

Q. Was there scepticism at that time amongst the doctors at the Royal Free about the safety of prophylactic treatment?

A. A little bit because there was a worry, which still exists to a far lesser extent, that early prophylaxis might increase your risk of developing inhibitors, the antibodies to treatments which make you resistant to treatment.

There was also a worry that, of course, there is to an extent a dose response risk in relation to whether you get these viruses or not. Having said that of course, Dr Kernoff believed that all severe haemophiliacs would eventually become infected. So that was a lesser consideration which became possibly more relevant with HIV. There were some small reservations in those respects. The biggest reservation is: was this feasible? How are you going to give it two or three time a week treatment to little screaming babies

with very poor veins? It was really only with the development of indwelling right atrial portacath in the late 1980s and proof of their safety that we were able to replicate what was going on in Scandinavia.

Q. Thank you very much.

As we have your CV up in front of us, I just wanted to digress slightly to a different topic at this point and ask you about something you have talked about already, which is your involvement with the Haemophilia Society.

Could we go to page 6, please, of the CV? We see there under "Charity committees" that you were a medical adviser from 1997 to October 2005 to the Haemophilia Society. In one of your statements you have pointed out that you had contact with the Haemophilia Society when you were the haemophilia director at Yorkhill as well.

What did the role of medical adviser within the Haemophilia Society involve?

A. Yes. These are things I have been trying to remember and I think it was nearer to 1987 than 1997 that I became the adviser, because I certainly was contacted by Dr Evans, who was the chairman, when I was still in Glasgow but, you know, they will have records of that.

Yes, obviously Philip Dolan was, I think, an extremely good advocate for the Haemophilia Society.

There were many contacts at that stage and for years thereafter. The role of the medical adviser was to provide independent advice to the Haemophilia Society about medical events and to keep them up-to-date et cetera, but to work as their advocate, if you like. And I very well remember the phone call from Dr Evans saying, "Look, we are not interested in having any more doctors on our panel who just adopt a sort of prowl mentality. We don't want that. We want somebody who is there." I have to say my impression of the medical advisers when I joined was that they were strong patient advocates actually and provided independent advice which wasn't always, you know, just sticking by what everybody in the medical fraternity might be saying at the time. They didn't make decisions for the Haemophilia Society, they were there literally to give them advice. At this stage, when I was there, the vast majority of the time was spent talking about viruses and how you manage it and how you, you know, avoid it, et cetera.

Q. At that time, would it be fair to say that the Haemophilia Society members, whom you were advising, were dependent on your advice for information about the safety of products?

A. Partly so, yes. You know, obviously these were often very intelligent people who had other means of finding

out about safety, but things weren't always as widely in the public domain as they are nowadays, so you couldn't necessarily get yourself, as a haemophilia person, information that was only available to haemophilia directors via the UKHCDO et cetera.

So, yes, they did depend to an extent on what was being presented to them. As I have said many times before, it is a pre-Internet era, and therefore things like congress abstracts and outcomes et cetera, were not readily available to the general public unless they spent forever in the library. So there was much more dependence then than there would be nowadays probably.

Q. Against that background, Professor Hann, what would be the other means, to which you have referred, of Haemophilia Society members finding out about the safety of products, other than the advice that you were giving them?

A. Well, to be honest with you, I cannot remember how much of things like CDC, MMWR, et cetera, like that, was available to the general public at the time. That's the sort of thing that is readily available now. The UKHCDO do did provide some information, and I well remember them giving information to the Haemophilia Society as asked.

The Haemophilia Society was represented very

strongly at some open meetings of the UKHCDO but I imagine their best means of information was through the World Federation of Haemophilia, which was a unique meeting in the early era; the Haemophilia Society being one of the oldest patient/parent support groups. This was a meeting that was open in almost every respect to patients, all healthcare professionals, and those sessions on HIV, et cetera, were attended by members of the Haemophilia Society and persons with haemophilia themselves.

Q. Would it be correct to say that the sessions that you have referred to would be sessions in which information was given by doctors to patients?

A. Yes, there were but there were also Haemophilia Society meetings and you know, the chair of the meeting would be the Reverend Tanner et cetera. They were fully involved, but, yes, mostly it came from the medical profession who were in possession of those facts.

Q. Okay. Thank you very much.

Could I move on now to ask you some questions about your experiences at Yorkhill, and first of all your arrival there. You have given a good deal of evidence about this already and you have explained in particular the fact that when you arrived, I think it would be fair to say, you were spread very thin over a number of

different departments, that you were doing a job which I think latterly was done by three consultants.

I wanted to ask you whether the administrative pressures that were imposed upon you, in your view compromised to any extent the quality of the care which the hospital was able to offer to its haemophilia patients?

A. With regard to haemophilia, I would have spent more time in the haemophilia field, in the leukaemia field and the solid tumour and the brain transplant et cetera. Yes, I was too thinly spread in every area. I think you say three, I think there were four or five consultants there, but it was a job, at that stage, for a minimum of three people.

Q. What I was trying to get at is whether in your view that administrative arrangement impacted in any real sense on the quality of the care that the haemophiliac patients received?

A. I don't think that it did. I think that the greater impact was the lack of physical resources, et cetera. We were very fortunate in having Dr Pettigrew there and the haemophilia sister. The social work counselling input was not ideal. I would like to have spent more time personally with the parent support groups, speaking to individual patients' parents et cetera, myself.

So in that respect I think there was some -- I would

hope quite limited -- impact by the fact that I was trying to wear about six hats at the time.

Q. I think you should have a copy of your transcript, professor. I want to ask you in connection with something you talked about on this subject on page 26, going over to page 27. If we could have that up on the screen, please.

A. Of what, sorry?

Q. This is the transcript of your earlier evidence, the bottom of page 26. You were asked --

A. Just a second, sir.

Q. Sorry. (Pause)

A. Right.

Q. You are being asked there about the approach which you adopted when you arrived at Yorkhill, and you said:

"This was an era when we had gone from basically each doctor doing it his own way, almost to a much more protocolised approach to things. It was in its very early inception but because Dr Pettigrew wasn't always there, because I had many other things to do, it was important that there was guidance for those people who weren't particularly expert in this area, so we followed the best practice at the time, if you like."

I wanted to ask you first of all, what you meant when you said at this time there was a more

"protocolised approach to things".

A. Yes, I'm not talking here about the psychological -- whatever, it's basically how do you manage the patient with a haemarthrosis of the knee. You know, what sort of levels you get to, how you calculate the dosage et cetera. There was no unit in the UK at the time, including the Royal Free, that was not covered at night or at weekends by people who were not experts in the area. Sorry, too many negatives.

But you would always have to accept the fact that there would be non-experts at the time who had access to a consultant but who might need to know, for instance, how you treat pain in the knee in a haemophiliac, you know, what should you be aware about with regard to life-threatening bleeds, what dosages, how you work out dosages, and what type of product, for instance, to use for Haemophilia A versus B versus von Willebrand's disease, et cetera. Could it be that you could manage these patients with tranexamic acid, DDAVP et cetera.

None of this was written down when I came there and that was not unusual, but I had come from an extremely well organised international reference centre which had gone down that line and I was very impressed by it. I was also working in the area of leukaemia, where for a few years only -- and this was pretty unique in

Merson(?) -- the treatment protocols were actually detailed and set down and could be followed as a standard working practice, if you like. This was all new medicine but I felt very strongly that we had to have that.

So that was what I mean by a "more protocolised approach". There is an additional advantage of that, of course. If you treat patients in a standard way, even if there isn't an actual national guideline, at least you know what you have done and you can change things to a better approach, if needs be.

Q. Thank you. Could.

I ask you some questions about something, again, that you have talked about to a certain extent already, which is the process involved in the selection of products in the treatment of your haemophiliac patients. I think you have said already, as was the position of Dr Pettigrew, that your preference when you arrived at Yorkhill, was to use SNBTS concentrates to the extent that that was possible. Is that an accurate reflection of the position?

A. Yes.

Q. The position from the information that we have statistically is that in around 1980, in terms of Factor VIII concentrate use, before your arrival about

85 per cent of the factor concentrate that was being used within Yorkhill was commercial concentrate. Do you have an insight into why it was that at that time the usage was so high?

A. I won't go into all the detail of what I have said before because it's there in the transcript, but basically I had one or probably two conversations with Dr Willoughby about this because I was somewhat concerned that although I had come from, as you know, units that were almost entirely commercial treatment-based, because that's all we had in England, largely, basically his attitude was that he had been let down by supply in emergency, that there was not enough for prophylaxis. And as I have said, he was ahead of the time in regard to that, that, as you have heard from Dr Forbes, they needed to use significant amounts of cryoprecipitate, et cetera, on the adult side, that he was concerned about low purity and poor recovery and that he felt that it was difficult to draw up because of impurities and wastage was significant, and that there had been several patients who had had significant and severe reactions to the SNBTS Factor VIII.

Also, you know, when I said, "Well, this is American-derived and all that" and I didn't know at the time what the supply was like in Scotland, but I said,

"Is it not possible to use the Scottish product?" he basically said, "The donor pool has been improved in America. Hepatitis B is far less of a problem. Hepatitis C, there is no evidence it is going to be a severe disease. So that's the supply. We can get it. The authority is funding it, so you will never run into difficulties with it. It's a more pure product. It's readily available, less reactions. That's what we have chosen to do."

Q. The statistical material which we have suggests -- I have already quoted a figure for 1980 -- that in 1981 the figure had dropped to somewhere around 58 per cent and in 1982 the figure was around about 48 per cent. In the first year in which you were the centre director at Yorkhill, the use of commercial Factor VIII appears to drop dramatically to a figure of somewhere just above 3 per cent. Does that reflect a conscious decision on your part to stop using commercial concentrates in favour of the SNBTS product?

A. Yes, and for the reason that I have already stated: both cost effectively, economically and for the possible -- probable, depending on who you listen to -- lesser risk because of the hopefully better donor pool, that's what I want to do. But there were several caveats to that which I have said in my evidence already, one of which

is that I was also brought up not to chop and change products too much because there is no doubt that when you do so, there is a small risk of inhibitor development, which is a devastating development because it makes the patient largely in that era untreatable.

Also there were some patients who had severe reactions and there were some -- there was a worry in Scotland of using the SNBTS product for major procedures where there had been some evidence of not adequate recovery in the body and possibly bleeding problems as a consequence.

But, you know, I had all those worries in my mind but at the same time for me the lower risk of infectivity was the paramount one.

Q. Thank you. Could I ask you to have a look at one of your statements that I think we have had a look at already? This is PEN0120203, and in fact I'm looking at the second page, which is 0204. Could we have that up, please?

A. Paragraph which?

Q. This is paragraph 5 but I'm looking over the page, at the top of the second page of this two-page report, and this is a paragraph in which you are talking about this subject and the attitude which you held towards the use of products when you arrived at Yorkhill. You said:

"I thus did everything I could to minimise pooled plasma product use throughout the hospital and not just in the haemophilia centre, as we knew that cardiac patients, leukaemia patients and others were at risk."

A question I wanted to ask you about that -- it may be a misunderstanding on my part: does that suggest that there was a exposure amongst the non-haemophiliac population to pooled plasma products?

A. Yes, there was some, and a large exposure to non-pooled plasma products.

Q. In relation to pooled --

A. Which was also a risk.

Q. What exposure would non-haemophilia patients have?

A. Well, the biggest use group would be cardiac. You know, these are patients who are getting bleeding problems post surgery, very complex, very high risk surgery in congenital heart defects, but there are also surgical patients who were bleeding and being treated with mainly fresh-frozen plasma, cryoprecipitate, which was to a certain extent pooled.

My memory isn't very good in this area but my memory is that cryoprecipitate was to a certain extent pooled, maybe ten persons per unit. I can't exactly remember. But whatever we knew subsequently, of course, the risk was of the order of 1 in 1,000 for donor units with

regard to non-A non-B hepatitis. That was in retrospect.

There was a small amount of usage of pooled concentrates in patients who were bleeding with life-threatening bleeding, in order to replace, for instance, Factor VIII in patients with disseminated intravascular coagulation, et cetera. Of course, this was something that we monitored as closely as we could. But again from the HIV era this is something else that we learned, that you have to have what's now called "haemovigilance" and we just didn't have the resources to do that in that era in any formal fashion.

Q. You go on to say in that paragraph, just about half way through it, starting at the word, "However":

"However, my memory is that we did not have enough SNBTS factor concentrate to deal with all the emergencies and significant operations, eg on patients with inhibitors or those needing orthopaedic procedures."

Would I be correct to say that in those circumstances, where you didn't have enough, you would rely on commercial product?

A. Yes, but I have to say that then SNBTS did everything they could to help us and so the usage -- that's why I was able to drop dramatically -- and possibly to the

detriment of the Royal Infirmary. As far as I remember, they gave preference to us to change this from a commercial to a SNBTS-using unit. There were episodes where we could delay operations because they weren't emergency and we did that.

Dr Crawford, Bob Crawford, was our main contact and he was as very helpful as he could be. But at that time, because of the increasing evidence that we should move away from commercial concentrates, we actually stopped prophylaxis in some patients because of that. You are weighing up there does prophylaxis really work on those patients and the evidence in that era was ambivalent. Should we be exposing those persons to commercial concentrates?

If they were having recurrent severe bleeding problems, then the balance would tip towards using commercial concentrates. If they, for instance, had developed an inhibitor, then you have no choice but you use whatever you have there because the bleeding is life-threatening.

When it came to things like surgery, then, if possible, we delayed the surgery and used SNBTS product.

Q. Would it be fair to say that, given the fact that you were using just over 3 per cent commercial product in 1983, the issue of patients with inhibitors was not

a particularly large one in the context of all of the patients you were treating?

A. No, but I'm almost certain there was one patient with an inhibitor. The use of concentrate in inhibitor patients is dramatically more than in other patients. We are talking about tens of thousands of units a year, using ten times dosages, in order to try to overwhelm the inhibitor. So the use of that single patient can overwhelm the whole population, to an extent.

We had one patient -- I'm afraid I can't remember when -- during that period of time. It's possible that that patient required some commercial concentrate because it was the least worst option. I don't remember but that would be a possible scenario.

Q. Is it possible that that patient could have used all of the 3.19 per cent of the total factor concentrate?

A. Yes, or that that was that patient that had severe reactions to the SNBTS product. I don't remember.

Q. Thank you.

A. But, yes, that is my best memory actually, but I'm guessing to an extent.

Q. Thank you, professor. You have touched on prophylaxis, which is something I would like to come back to, but could I just stick with this statement just now? You say in the final paragraph:

"I have not retained the details, but we would source factor concentrate products that we believed carried the lowest risk, bearing in mind that, in the absence of a test defining safety, this would mean going mainly on the product's record and any reports of adverse events if they came through the UKHCDO."

You have already made some comment on this but I just wanted to ask you whether commercial products were ones in connection with which there had been reports of adverse events or in connection with which there was a bad record at the time when you came to Yorkhill?

A. Not at that specific time, although -- it's easy to get memory recall from reading things but I have a memory that there was a worry about Hemofil to an extent. Certainly not long after I was at Yorkhill there was an episode of a recall of Factorate maybe -- that being the commercial product Factorate -- because of an association with an acute episode of hepatitis.

Those are the sort of events I'm talking about. Later on there were episodes of Hepatitis A in Ireland, for instance, in other products. So those are the types of events that we really would respond to immediately.

Q. Thank you very much. I'm going to move away from that statement just now and I would like to move on to

a slightly different topic, which is the administration as regards the ordering of products. Again, this is something that you have commented on to a certain extent in your evidence but I would just like to ask you a few more questions.

THE CHAIRMAN: I'll interrupt you before you go there, Mr Dawson.

Professor, you have mentioned that blood products would be used other than in the treatment of haemophiliacs and I understand from Professor James that people who do have major operations lose clotting capacity and that they therefore require a supplement. Do you have any feeling for the sort of proportion of use of blood products in the case of non-haemophiliac treatment as against haemophilia treatment?

A. Yes, I'm talking about plasma products here. Obviously, red cell use is vastly more in the non-haemophilia.

When you talk about plasma products, again separate it out from concentrate because concentrates would not be used very commonly in non-haemophilia sufferers.

Basically, the only relatively common use there of a concentrate would be a fibrinogen concentrate, which is used up in those circumstances, but occasionally we would also use Factor VIII concentrate because Factor VIII is one of the factors that's consumed when

you get this so-called "consumptive coagulopathy disseminated intravascular coagulation", or "DIC" -- too much of a mouthful -- for short, which happens quite commonly after cardiac operations, for instance, because they become septic because they have long periods of hypothermia, et cetera, et cetera.

But that's not all. There are, for instance, women who get DIC during child birth and so on. So there is an exposure of concentrate which is far less than in haemophilia, far, far less, like 1 per cent, 2 per cent, something like that. But the use of non-concentrate plasma products, cryoprecipitate and fresh-frozen plasma, in particular, would be higher in the surgical area, in my unit anyway, than in the haemophilia area, whereas in some units, like the Royal Infirmary, where they are having to use a lot of cryoprecipitate, then maybe it wouldn't have been that way round.

THE CHAIRMAN: Thank you very much.

The other question that I would like to ask arising out of Mr Dawson's questions so far relates to the pressure on you and your colleagues at the time. He has concentrated quite naturally on the impact on haemophilia care. Was the care of the haemophilia patient affected to a significantly greater degree than the care of the leukaemia patient and the other groups

within your ambit?

A. I am afraid it was largely the other way round. The fact is that leukaemia, solid tumours, brain tumours, bone marrow transplant, is a minute by minute problem. They can be well one minute and they can be bleeding to death, septic, dying, the next.

As a single person you can't be on the ward providing -- I mean, it would be a joke to say this was consultant-led care, a bad joke, and nowadays, obviously, consultant-led and often delivered care is the norm. In that era you were more than of an orchestrator, a conductor, than a provider of clinical service on a minute by minute basis.

So, no, haemophilia was a chronic disorder. The time limitation that was upon me limited the amount of, if you like, talking time that I had rather than anything else. If there was a need for me to see something whose knee was swollen or whatever, then I could always go there and say, "Yes, do this, follow that protocol." What I did not have time for as much as I would like is the parent support groups, seeing everyone in the haemophilia clinic as frequently as I would like. The clinic hadn't existed before I was there, by the way, and the day-to-day time on the day care. But they had very good care on the whole.

The deficiencies that existed occurred in casualty, which is a problem area always at night, and when Dr Pettigrew was away, when I had to divide myself up, if you had a good trainee, that would be fine; if you had a trainee who was very inexperienced, it wouldn't be ideal. So that's where the deficiency lay.

THE CHAIRMAN: Thank you very much.

Mr Dawson?

MR DAWSON: Thank you, sir. I was just moving on, Professor Hann, to the question and questions about the administrative system for the ordering of products. I'll just clarify, first of all, my understanding of your position about who decided in principle which products would be used. That was your decision and you have explained already that your general philosophy, when you arrived at Yorkhill, was that you tried as much as possible to use the PFC product. Is that correct?

A. That is correct.

Q. As regards situations where commercial product was necessary, who decided which commercial product would be purchased?

A. I mean, again it would be me but there was a stock control point of view, which I think has been alluded to you in some of your -- this is very expensive product and obviously that's not the first consideration,

otherwise you wouldn't use commercial product in the first place probably, but the fact is, if you have got thousands of units of Factorate there and it's in date, then you use that. You don't say, "Let's go and use something else."

I can't ever personally remember ordering in new commercial concentrate. It may have been the case that we would do so. If that was the case, then we would have just stuck with the product that we had been using before for the reasons I have already alluded to because of the risk of inhibitors, et cetera, and because you can react to one product and not the other.

As far as I remember, the costs across the board were roughly equivalent anyway, but the vast majority of ordering was done through the Blood Transfusion Service. I don't recall having to order a commercial product. If we did order commercial product, then it was probably done by the senior chief in the blood bank in liaison with the unit manager/treasurer of the hospital and basically we just stuck with what was used.

Q. You have made reference already to the Armour Factorate product. Is there any reason why the Armour product would have been preferred in the treatment of children at Yorkhill, as far as you are concerned?

A. There is no reason that I know compared with other

commercial products, unless you had felt that the, I think, Baxter, product, Hemofil, had got itself a bad name because of the publicity, which was sort of vaguely, vaguely in the back of my mind, I think.

But there was a problem with all plasma donation at this time in several respects. So the deciding factor, if we ordered any, was that you stuck with what you had used.

Q. But there is no clinical reason or anything like that why the Armour product would be favoured over any other commercial product available at that time, as far as you are concerned?

A. Obviously in a later era you had much higher purities, et cetera, so therefore you had lots of debates about which purity concentrate you had. Then there were differences in price and then we went to European tendering and all of this changed again as part of this era.

As I say, I do have a vague recall that there was a particular worry over the use of Hemofil at the time. Whether that was justified in overall clinical terms compared with the other commercial products, I just don't know. As far as comparing it on a clinical purity basis or reaction basis or whatever, there was no evidence to support a difference.

Q. In her statement Dr Pettigrew made reference to ordering being done by a senior chief technician in the haematology department. In her evidence she recollected an individual called Mr Jewel in that role. Do you recall his involvement in the ordering of products?
A. I don't and, to be honest with you, I'm just reiterating what she said. I do know Mr Jewel. I did know him well. He retired a couple of years later but, yes. I think that was just because, if you like, he was responsible for the blood bank. This is a blood product, you know, it was stored as such. That was also the case at Great Ormond Street, when I went there. It was not that Mr Jewel was making a decision to order a specific product; that's not his responsibility at all. He was there -- if he was the person who did it -- to just logistically order it and make sure that it went through proper financial channels.
Q. Do you remember a sister working in the haematology department called Sister Wright?
A. I don't remember that specific person, no.
Q. Would sisters in the haematology department have any input into the ordering of products?
A. I don't think so. Haemophilia sisters did in fact subsequently develop into haemophilia clinical nurse specialists and did actually do that as part of their

job and when I went to Great Ormond Street, that was exactly what was the situation. I don't think that that was the case here.

Q. Thank you. Could I just refer you to one of your other statements? There are a number which you have provided to the Inquiry. This is PEN0150035. This is the document which is entitled "Professor Ian M Hann, response to Penrose Inquiry." Dated 5 June 2010. I think it's a response to a number of specific questions you were asked. I'm looking in particular at page 0037, which is page 3 of this document.

A. I'm sorry, I haven't got the numbering. Could you just give me the title of the section?

Q. Certainly. The title of the question?

A. Or question.

Q. It's the first question you were asked:

"Systems regarding blood products used."

A. Yes.

Q. Do you need any more than that or have you got it?

A. I have got it.

Q. This is the bottom of page 0037. You say:

"When it came to the use of commercial product, the plan would always be to use that which was available and which had a good track record. I cannot remember how payment for such products was actually organised within

the Health Service at the time within Scotland, but that would not, to the best of my knowledge, have been a deciding factor in any treatment decisions."

You say there that budgetary or payment considerations would not have been a deciding factor. Would they have been a factor in the determination of which products would be used?

A. If you are talking about commercial versus commercial, no, because I don't think I even knew. In fact I'm pretty sure I didn't know. The fact is that a great number of units within the UK at the time -- and I think probably within Scotland -- were unable to get -- we were in a fortunate position to be able to order this and were very much supported by the unit manager, who basically just said, "Go ahead and order whatever you need."

This was a very old-fashioned era. There was no such thing as tendering, there was no such thing as tendering committees or committees that looked at one thing versus another; it was up to individual consultants to decide what to do, essentially.

Q. But the position, as I think you have alluded to already today, is that commercial product was very expensive. Isn't that right?

A. Yes, but again I would not have even known what it cost

necessarily to produce the Scottish product if you factored in -- you know, did we even know at that time how much it cost to produce a unit of Factor VIII if you actually were tendering versus a commercial organisation on a commercial basic. Certainly, when I was in the UK, we didn't know that -- sorry, in England. In England at the time the Blood Transfusion Service would say, "Oh, it costs so much for us to produce this." But is that really all the overheads, et cetera, on a commercial basis?

So the answer is I would be surprised if the commercial concentrates weren't a roughly equivalent cost. I'm sure they cost considerably more than the SNBTS product, which was one of the drivers, obviously, to try to become self-sufficient. But we were not aware at that time of real commercial costs across the board.

Q. There has been a suggestion in some of the evidence which the Inquiry has heard to this point -- and this may be a matter of administration more than anything -- that where a hospital was using SNBTS product, there wouldn't be any direct cost to the hospital for that but that the hospital would be responsible for the purchase of any commercial product which it wished to use. Is that your understanding of the position or is that not accurate?

A. I am afraid I just can't remember. My feeling is that the hospital paid for commercial products and that there was no specific deduction from the hospital for SNBTS products. So, therefore, you would be sort of mad in a way not to use them if they were safe. But I could be wrong there.

What I know is that subsequently in England cross-charging came about. But certainly in England in 1988 or 1987 there was no such cross-charging. So I doubt that it had occurred in Scotland by then. But that's speculative.

Q. Thank you. Could I just move on to a slightly different topic, something we have touched on already, basically relating to prophylaxis and the position of Dr Willoughby in that regard?

You have given some evidence about that already and I think you may have repeated today as well that he was very keen on prophylaxis. Could I just ask you whether it is an accurate representation of your understanding of Dr Willoughby's attitude towards treatment that it was based on a desire to treat children prophylactically with concentrates and also a certain concern which he had about the purity of domestic products? Would those be the major themes, as you understand it?

A. Yes. The supply, obviously, yes, and all of that, yes,

all of those factors.

Q. And presumably the position was, as I think you have already outlined, that he required to rely very heavily on commercial products, principally because of the fact that he wished to treat children prophylactically. Is that right?

A. I wouldn't say principally. I think there were two or three main reasons: one, that he had patients who had had reactions who he couldn't treat with the product; two, that there was a need for prophylaxis and he couldn't get supply for such; and, three -- I mean, he made it very clear to me that he had been let down in an emergency with inadequate supplies. I don't know when. That's all I know.

Q. How much more product is required to treat a child prophylactically, as compared with non-prophylactically, if that makes sense?

A. It obviously depends on their age, but three times in the randomised trial.

Q. How many haemophiliac patients were there in your care who were on prophylactic treatment at the time when you arrived?

A. There were roughly six or seven, something like that.

Q. I think you have made reference already, in response to some of the questions from the Inquiry counsel, to the

fact that you required to curtail the prophylactic programme, if you like. Why was that necessary when you arrived?

A. Right. The reason was twofold. First of all, the evidence that it worked in the circumstances that he was using it was not compelling at the time. It turns out that he was right, and in fact in my own defence, if you like, I was the first to show that in the non-Swedish group. What you have to do is persist with it. The fact was that some of these patients were receiving prophylaxis with no or very little benefit and were using vast amounts of product and it was becoming very difficult to give it two or three times a week. We had also not learned how to use it properly and manage the levels adequately and such like. So that was one reason.

The other reason was that there simply was a lack of supply, related to a number of events. First of all, we had a number of patients who at virtually the same times developed severe problems with their knees, with their synovium, and required synovectomy and used huge amounts of Factor VIII. And there was a patient subsequently -- I can't remember when -- who developed an inhibitor and who required emergency treatment for what's called a compartment syndrome, where there was compression, I

think in the arm, and used huge amounts of Factor VIII during that period.

So I would be reluctant to be critical of the SNBTS because what you do when you have what is a semi-commercial venture is produce a volume of product, and our product had huge blips in it. So basically we had to stop prophylaxis in this circumstance.

Could I just make one other point? There are two main types of prophylaxis. There is the type that Dr Willoughby was keen on, which is called "secondary prophylaxis", and there was the type that eventually proved to be the godsend, which was primary prophylaxis; in other words, starting treatment at a very young age and preventing bleeds. So one is truly prophylactic and the other, which Dr Willoughby had approached, was not truly prophylactic; it was settling down a very, very troublesome problem and trying to reduce or even prevent further bleeds and further joint damage.

Secondary prophylaxis, which he had adopted, proved to be very, very difficult and require at least three years of treatment before it showed much effect. We published that under the first name of Liesner from Great Ormond Street a few years later.

So the answer is, yes, supply would never have been

enough. Also, there was some lack of belief that continuing was going to be of benefit to those patients.

Q. The six or seven boys whom you have mentioned as being on prophylactic treatment when you arrived, they would have been on prophylactic treatment with predominantly commercial concentrates before your arrival. Is that right?

A. Oh, yes.

Q. And how many of them went on to develop HIV infection?

A. I don't know the answer to that, I am afraid. I don't know. I can't break it down. Out of the ten or whatever it was who developed it I'm sure there were some that did and some that didn't but I don't know the exact numbers.

Q. Okay, thank you. You have mentioned the numbers infected there. So I'm just jumping to that because I wanted to ask you some questions about that too.

Basically, as I understand it, your position, when asked questions by Ms Dunlop previously, was that she had sent you a schedule which indicated that there were 21 individual children who had been infected at Yorkhill, and I think your reaction to that was that you thought that that figure was a bit high and in fact, as I think you have just mentioned, your recollection was a figure nearer 10.

I just wondered whether I could put to you a possible explanation, at least to a certain extent, for why those figures are different. In her evidence Dr Pettigrew suggested that, when testing was being done, you had some responsibility for testing patients who were no longer under the care of Yorkhill and had moved on somewhere else.

The figure of 21 that you were given indicates the result, as I understand it, of a collaboration between a number of different doctors in Glasgow to work out how one allocates the responsibility, if you like, for the place of initial infection. Is it possible that, at least to some extent, the divergence in the numbers is based on the fact that you are thinking of how many people in your care in 1984 were infected and the table shows how many people were infected at Yorkhill?

A. Yes, I'm as sure as I can be that that's the case and it's one of the reasons why I feel -- and I'm not devolving responsibility from myself. It's one of the reasons why I feel that I didn't initiate the first set of testing because there is no reason why I would have initiated testing on patients who have already transferred. It was quite right that it was done, I personally believe. I don't know the process, and I'll take responsibility for it, but I don't see why

I should have initiated testing on patients who'd gone elsewhere. I think that it's very unlikely. We know from at least my recollection -- and the publication at the time was from the Royal Free, which I continued to be in touch with -- that the vast majority of infections were between 1979/1980 and 1982 or the end of 1982 sort of period, and so a number of the patients would have been transferred. My best memory -- and I think it's probably Dr Pettigrew's best memory as well -- is that we were still looking after about ten. One had gone somewhere else altogether, I think, and the other maybe ten had gone on to the Royal Infirmary. We certainly had transferred quite a few patients in the year or two after I went there because they were sort of getting rather long in the tooth.

THE CHAIRMAN: Mr Dawson, I think I'm getting rather long in the tooth too. I'm not sure that I'm learning anything new from this passage of evidence. I am, of course, absolutely sure that your time is running out.

I wondered if you might just take care and restrain this line.

MR DAWSON: I was going to move on from that. The particular reason for that question, sir, was just to try and see if that was some explanation for the anomaly in the numbers. But I'm moving on.

You were asked some questions earlier, Professor Hann. I would just like to ask you a couple of brief matters on the use of cryoprecipitate at Yorkhill. There seems to be a number of references in the paperwork to the fact that cryoprecipitate might be used for younger children. I wonder if I might just be able to explain why that might be an appropriate choice for it to be used for younger children.

A. I suppose for two reasons. One is that younger children in that era, certainly up to about the age of at least five or six, were usually treated in hospital because we didn't have indwelling catheters, et cetera, and therefore the many problems of using cryoprecipitate at home, which basically meant you couldn't do it in the vast majority of cases, could be overcome.

Where you could not give cryoprecipitate a clean bill of health because of the Rickards, et cetera, you could say, especially if we could go down to a single donor, unpaid donor, Scottish donor use, then we can minimise risks. So the problems of volume, reactions, logistics, getting the needle in, et cetera, et cetera, were much easier in that group. That didn't always work, of course, because the volumes could be too great and the veins too difficult it meant sometimes that we did have to use concentrates in those patients.

The second consideration, very briefly, is that if, certainly going towards 1984, you are talking about a population that might already have been infected, then I suppose the greatest protection you want to give is to the youngest patients. Yes, I suppose ...

Q. Thank you. On the issue of cryoprecipitate, you were asked some questions earlier in connection with the possibility of treatment reverting to cryoprecipitate, I think, in 1984, and you discussed the circumstances surrounding that being suggested.

What was the reason for you suggesting that patients might revert to cryoprecipitate in 1984?

A. Basically, it was because by the latter part of 1983 we were becoming more convinced that this was a blood product transmissible disease, that although people were saying it's one in 1,000, et cetera, 1 in 500, would maybe develop AIDS, we had to do everything we could at that awful interim stage, no matter even if it was just theoretical or possible or whatever it might be, to reduce risks. So that was one of the things that was proposed. I remember it quite well. It was, I'm almost sure, Arthur Bloom and Peter Jones who suggested it towards the end of 1983, and that's about that time of early 1984 that some patients reverted to the use of cryoprecipitate. But it meant a major change in

lifestyle, giving up home therapy, et cetera, in the majority of those cases.

Q. Which types of patients -- and I'm thinking typically about the severity of haemophilia -- would that have been suggested to?

A. Obviously, we had for some time been trying not to treat mild and moderate patients with concentrates during this era, especially mild patients. As far as the severe patients were concerned, it was logistically much more difficult and virtually impossible on a home treatment basis. I don't think any persons in this era were able to manage home treatment with cryoprecipitate and therefore they became hospital-based patients again, and with the information coming out of the Haemophilia Society and the logistical difficulties, et cetera, there were definitely some who continued their use of concentrates.

Q. Was there any consideration, as regards severe haemophiliacs, given to the possibility of reducing the amount of concentrate they were using at that time?

A. Yes, there was. I know from speaking to the adult treaters that there were a number of adult haemophiliacs who basically stopped treating themselves and turned back to the Tsarevich approach -- you know, just rest and all the rest of it -- and there was a little bit of

that in the paediatric area as well.

From our position as treaters, we would discourage that approach as much as possible and if there were serious concerns and if it was feasible, we would certainly revert to cryoprecipitate as a somewhat safer approach --

Q. Okay, thank you very much.

A. -- theoretically.

Q. Could I just move on to ask you a few questions on the B5 topic? I think most of the matters I wish to cover with you have been covered already this morning. However, could I ask you first of all a couple of questions about information that would be given to parents of children whom you were treating in the early 1980s about product uses. In particular, could you tell me whether ultimately it was your decision as to what products would be used for the children and whether the parents had any influence over that?

A. Yes is the first answer but, of course, they were informed and aware from myself and the Haemophilia Society, et cetera, of the position they were in. There were lots of discussions with parents whose -- for instance, if their children had had reactions or severe reactions to the SNBTS product, whether they were prepared to go back on that product again. I'm pleased

to say that in fact, I think, almost in all instances we were able to do so with some pre-medication, et cetera, as required, and then the purity improved.

So, yes, there were lots of discussions of that nature.

Q. So if a parent were to say to you that they wanted a particular product to be used, for example they wanted cryoprecipitate to be used rather than concentrates, would you have acceded to that request or would there have been other considerations?

A. Yes, absolutely, but we would have to make them aware that that was something that only very rare parents could achieve at home and if they were prepared to go down that line, then we would try to support them but it was exceedingly difficult and it would change -- I hope that we weren't totally discouraging in this respect. We would have to point out the pluses and minuses.

Q. Okay. Could I just ask you a couple of quick questions about the topic you have touched on already, which is information given to patients and their parents about test results.

Could I just ask you: why did you think it was important that the information about the testing and the results of the testing be communicated to patients and parents?

A. Two reasons, I think: First of all because there was a need to know, and a need to know had many aspects, including sexual health, et cetera, but also from our point of view it was necessary to know because, as I have said in my statement, otherwise you are managing a problem blindfolded. We knew more and more as time went by of the sequelae of HIV infection, whether it be Kaposi's sarcoma, pneumocystis, whatever it might be. If you are in the dark about those things, there is no possible way. You can die within days of pneumocystis and just present with a cough. We knew that from leukaemia treatment. So we needed to know.

The second aspect is that I just felt ethically that that was the best approach for reasons that we have already discussed. I think that being secretive with families is hardly ever justified, unless you are doing more harm than good by doing so.

Q. This is my final question, Professor Hann. In your view would it have been appropriate in late 1984 to have a meeting at which patients and families as a group were told that some of them had been infected and that they could come and ask about specific details if they wished to do so?

A. In my view, the way you deal with this -- and I have already held my hands up and said we didn't do it

perfectly by any stretch of the imagination and that's my responsibility.

The fact is, if you tell a family that their child or a patient adult has a serious disease, you tell them, you don't tell somebody else, or whatever. I don't know the circumstances of this meeting. What I know is that you communicate such things.

This came up again with Hepatitis C. Do you write people a letter saying such and such or how do you go about it? And with Hepatitis C it was very difficult because they had only had minor contact with the hospital. We did it through GPs and GP nurses, et cetera.

You don't do it in some sort of very impersonal way. I was dead against writing letters to people, I was dead against doing it other than face-to-face and in as kind a way as is possible and as informative a way as possible.

Groups have a very important role with regard to support, with regard to information, with regard to all sorts of things, but it does not have a role in informing people about individual issues with regard to medical diseases.

Q. Thank you very much, professor. Thank you, sir.

A. Thank you.

THE CHAIRMAN: Mr Anderson?
MR ANDERSON: I think not, sir, thank you.
THE CHAIRMAN: Mr Sheldon?
MR SHELDON: I have no questions, sir.
THE CHAIRMAN: I think that has to be it.
A. We do have a few minutes' latitude here if you want.
MR GARDINER: I have nothing further, thank you.
THE CHAIRMAN: The temptation is great, Professor Hann. You have been extremely helpful and have, I'm sure, tried to answer all these very difficult questions to the very best of your recollection and ability. I'm very grateful, thank you very much, but we won't keep you longer than we need.
A. Thank you.
MR GARDINER: I wonder if I can bring up something about timing.
THE CHAIRMAN: We are sitting again at half past one.
MR GARDINER: We were planning to. I wonder if we could propose 1.45. We are quite keen to propose 1.45.
THE CHAIRMAN: If the witness is available at half past one, why?
MS DUNLOP: Fine.
THE CHAIRMAN: Half past one.
(1.01 pm)
(The short adjournment)

(1.30 pm)

ELAINE

Questions by MS PATRICK

THE CHAIRMAN: Good afternoon.

MS PATRICK: This is Elaine.

THE CHAIRMAN: Elaine, we just start right away without any preliminaries. But Ms Patrick will introduce all the people here and tell you what's happening before she begins to ask questions.

MS PATRICK: Hello, Elaine. I would like to start by, as Lord Penrose says, introducing you to everybody in the room, so that you know who everybody is and why they are here. There is Lord Penrose on the bench and next to him is Professor James, the medical adviser to the Inquiry.

You know Margaret, the witness liaison manager, who is sitting next to you, and coming along the front row we have the two stenographers, who are noting down everything that's said this afternoon and that's for the transcript of the hearing.

Next to them we have Sarah Noble, who is the deputy secretary to the Inquiry and then Oli Stempt, who is in charge of documents this afternoon. So when I refer you to a document, it should appear on the screen in front of you and that will be Oli's job to make sure it gets

there. Next to me is Laura Dunlop, senior counsel to the Inquiry and next to her is Yasmin Shepherd, who is the paralegal to the Inquiry, who is helping us with this topic. Along this side of the room we have the lawyers who are representing the different parties interested in this Inquiry. I think you know the lawyers closest to me, who are representing the patients, relatives and Haemophilia Society.

In the middle we have the lawyers representing the health boards and the Blood Transfusion Service, and closest to you we have the lawyers for the Scottish Government.

You are being known for today's hearing as "Elaine" but that's not your real name, and a year or so ago you helpfully provided the Inquiry with a statement.

A. Yes.

Q. The statement number is WIT0040045. Do you have a hard copy of that in front of you? One is on its way but in the meantime, if you look at the computer screen in front of you. Is that all right?

A. Yes.

Q. In your statement you told us about your deceased husband [redacted]'s infection with the HIV virus from his treatment with blood products. In paragraph 1 of your statement, at the time you gave us your statement you

were 65 years old. Is that still the case?

A. No, I'm 66, nearly 67 this year.

Q. Okay. You and [redacted] were married in 1964?

A. That's right.

Q. Where did you meet [redacted]?

A. At the dancing.

Q. And was he good at the dancing?

A. Pardon.

Q. Was he good at the dancing?

A. Not bad.

Q. Can you tell us a bit about [redacted]?

A. He was -- at that time he didn't like drink. He was a man for going out in the fields. He loved animals. I think it was because he was in the hospital all his days as well, he liked outside all the time. Any time he wasn't ill, he was outside and completely, completely in love with animals.

Q. That's helpful. Thank you. You tell us in paragraph 3 of your statement that [redacted] was one of, is it four or five brothers?

A. Four brothers.

Q. That's a typo. And all four brothers had Haemophilia A?

A. Yes.

Q. You say that [redacted]'s haemophilia was quite severe and hardly a week went by when he didn't need treatment?

A. That's correct.
Q. Do you know that from having lived with him, that hardly a week went by when he didn't need treatment?
A. Sometimes it was a couple of weeks but very rarely much after. Maybe some weeks maybe just once a week he went to go over, other times it was two or three times in the week. It was not a set time.
Q. Right. Did [redacted] have other relatives with haemophilia?
A. No. It was just him and his brothers and in the end he just -- well, that was years ago. They didn't know much about it at that time. So the only answer I can come up with is maybe if mother and father had married other people, it wouldn't have happened. That was the only explanation they could have come up with at the time. They couldn't trace it at all.
Q. Do you know if [redacted]'s haemophilia was described as mild, moderate or severe by the doctors?
A. I think it was moderate. It wasn't mild and I don't know about severe, but it was at least moderate.
Q. Right. Do you happen to know what percentage of clotting factor that [redacted] had?
A. No.
Q. That's fine. Was his haemophilia similar to his brother's haemophilia?
A. I would say so.

Q. Yes. Well, you tell us in paragraph 3 that his treatment for haemophilia was very similar to that of his brother?
A. Yes.
Q. You will be aware that the brother you are talking about there also provided a statement to the Inquiry?
A. That's correct.
Q. We are going to have a look at that. You tell us there that from a young age [redacted] was treated with bed rest, then he was treated with plasma and then with factor concentrate. And you think that he started using plasma and factor concentrate about the same time as his brother?
A. Yes.
Q. The brother who provided the statement?
A. Yes. His brother would know more about the clotting factors and things like that.
Q. Yes. Well, I wonder if we could have a look at his brother's statement now, which I think you have seen?
A. Yes.
Q. You have and it's WIT0040136. What was the age difference between --
A. Two and a half years.
Q. I think we will see from paragraph 2 that this brother was the youngest of the four?

A. Yes.
Q. Yes. He tells us that he was diagnosed with Haemophilia A when he was born and his haemophilia is classified as moderate?
A. Yes.
Q. So does that bear --
A. I would say they were both the same, I would say.
Q. They were both the same, okay. He says there he had three older brothers, all of whom had Haemophilia A. One of his brothers died in 1961 as a result of a motorcycle accident when he was 21 years old.
A. I didn't know him. I wasn't married at the time. I knew of him but I didn't actually know him.
Q. Then he relates that his other two brothers, one of whom is [redacted], died from AIDS having acquired the HIV virus from infected blood products. I think he is talking about [redacted] first when he says he was 48 years old?
A. 47.
Q. 47?
A. 48 that year. He died in the February and he would have been 48 in the June.
Q. So [redacted] was 47 when he died in February 1992 and the other brother was 42 years old when he died in about 1995?
A. No, that's not right, no.

Q. Is it not?
A. His other brother was older than [redacted].
Q. Was he?
A. Hm-mm.
Q. But he also died as a result of AIDS?
A. As far as we know because they were estranged. They didn't talk for years, that other brother, but, yes, I am positive he did. He would maybe be 52 when he died maybe, he definitely wasn't 42.
Q. Could we move down the page, please, to paragraph 4, where [redacted]'s brother tells us about his treatment for haemophilia as a child. He says that he was first treated for his haemophilia when he was about three or four years old and was treated at the Princess Margaret Rose Hospital, Edinburgh under the care of a DrStirling. Do you know if [redacted] was treated at Princess Margaret Rose Hospital?
A. I know they went to the Princess Margaret. I know there were three hospitals they went to, because their mother and father used to have to often, at that time, get a taxi, get the ferry at that time and then get a taxi. They would spend ten minutes with each of them at the three hospitals. Sometimes the three of them would probably be in hospital at the same time, and I know they went round to two or three hospitals in that one

period to actually see them, to give them ten minutes each or something. I know that. And the Princess Margaret Hospital was definitely one of them. I know that.

Q. I take it you know these things from what [redacted] told you?

A. Yes, plus I heard his mother talking about that as well before she died.

Q. His brother goes on to say that his treatment initially consisted of mainly bed rest?

A. Yes.

Q. Is that what you heard from [redacted]?

A. Yes.

Q. Did he --

A. Even when I was first married to [redacted], a lot of it was just bed rest because there was nothing really out at that time. Maybe plasma later on but to begin with it was a lot of bed rest, a lot of bed rest.

Q. [redacted]'s brother says there that sometimes they would have to have bed rest for nine to ten months at a time?

A. Yes.

Q. Do you know if [redacted] spent long spells like that in bed?

A. Not as long as that when I married him, because that was 64, but at least weeks, four to five or six weeks, yes.

Q. Which must have been very difficult for a child?

THE CHAIRMAN: When he did have to have bed rest, was he able to get up at all after you married him, or was he very confined to his bed for weeks at a time?

A. When the haemorrhage was really bad, no, they couldn't get up at all, and in those days we didn't have duvets, it was blankets and sheets, and he couldn't even bear the weight of them. When I was first married to [redacted], I honestly didn't know what I was getting into. I didn't know about haemophilia. And I couldn't even walk across the room. [redacted] felt the pain.

THE CHAIRMAN: So even the vibration --

A. The vibration of walking across the room.

THE CHAIRMAN: What did you do about bedclothes, did you use a cage?

A. It was just bed rest at the time, until the haemorrhage went down and went away.

THE CHAIRMAN: But he would have to be covered in some way or he would get cold --

A. Pardon -- what they done was it was like a --

THE CHAIRMAN: A cage was it?

A. A wire cage where the covers would go over that to keep it free from his legs and that, because it was always [redacted]'s knees that haemorrhaged. He haemorrhaged other places but his knees were the worst, and nine times out of ten that's where the haemorrhage was.

THE CHAIRMAN: So you would have to feed him in bed and look after all his needs in bed?

A. Yes.

MS PATRICK: Do you know if he had spells of bed rest in hospital as well as at home?

A. Not so much when I married him because, as I say, he would rather -- sometimes they would want to keep him in hospital and he would say, "I would rather go home and bed rest".

Q. But as a child, do you know?

A. I'm sure he did.

Q. If we turn over to page 2 of [redacted]'s brother's statement, his brother describes also being treated with plasters on his legs and says that once -- this is obviously his situation -- he had calipers put on his legs to straighten them but this made the bleeds worse?

A. That's correct.

Q. Do you know if [redacted] ever had treatment like that as a child?

A. I think he had plasters. I think he told me he had plasters. I don't know about the calipers. I know his older brother, [redacted], he was in hospital for about six years at one time. The one that died. He was in the hospital about six years. They tried everything: plasters, calipers, everything. He was in for about six

years at one time. [redacted] was definitely in plasters, he told me that.

Q. So unsurprisingly, having heard about the extent of this treatment, [redacted]'s brother says he didn't go to school until he was six years old and he left school at 11 years old and together with [redacted], he was home tutored from then on?

A. That's right.

Q. This is obviously his brother, but you think that the treatment was similar. [redacted]'s brother says that in about 1956, when he was nine years old, he started receiving treatment with blood products?

A. As I say, I can't mind the dates of that. It definitely was about the same time as his brother.

Q. He says that he received treatment with blood plasma in about 1956 and from about 1959 he was treated with cryoprecipitate?

A. I would say so, yes.

Q. The amount of his treatment varied from year to year. Sometimes he would have two bleeds a year, I think this is when he is older and other years he could have ten.

He only receive the treatment in response to bleeds and I think [redacted]'s brother didn't feel that the cryoprecipitate helped him very much. So sometimes he would not go into hospital but try and rest at home

instead?
A. That's right.
Q. Did [redacted] do that too?
A. Yes.
Q. So did he try and avoid going into hospital?
A. Yes.
Q. He must have known his own condition very well. So did he realise --
A. He knew when a haemorrhage was coming on. He would go over and get the treatment or just go to bed straight away.
THE CHAIRMAN: What did he tell you that sort of indicated to him that it was about to happen? Did he tell you what he was feeling?
A. Well, it would be pain for a start.
THE CHAIRMAN: Right.
A. And I don't know the actual feelings inside him because -- it was definitely pain to start with and I think he would feel like blown up inside. It was definitely pain.
THE CHAIRMAN: What I'm interested in is the possibility that someone like [redacted] would have a sort of forewarning before the bleeding actually started. He might just feel something, because I have heard that suggested, you see, that they could sort of sense that the thing might

be coming. But you remember him having --

A. He definitely knew when he was going to take a bleed. He knew that. What he actually felt, I couldn't tell you.

THE CHAIRMAN: You couldn't tell that?

A. Because once they started the Factor VIII, whenever they knew it was coming on, they went straight over or by that time they had it in the house as well, taking it right away to try and shorten the length of it.

MS PATRICK: Looking at paragraph 5 of [redacted]'s brother's statements, he says that when he was 16 or 17 years old in about 1963 or 1964, he started receiving treatment for his Haemophilia A at the Edinburgh Royal Infirmary under the care of Dr Davies.

A. That's correct.

Q. That he was first treated with factor concentrate in about 1969 and he says it was like a miracle cure?

A. That's correct.

Q. Was that [redacted]'s view too?

A. That's right. I'm saying, when they knew the haemorrhage was coming on, at that time you went to the hospital, got it. I'm never saying they stopped haemorrhaging right away but it shortened the days they were ill with it.

Q. Could we now return to your statement, to page 2, which

is WIT0040046? How did [redacted]'s inability to go to school affect his life?

A. It didn't bother him. He was the kind of person -- he actually always says to me that the time he spent with the home tutor, that one hour/two hours, he learned more than he ever thought he would do in the classroom, because it was one-to-one and he always maintained that. And he wasn't a stupid person. He wasn't a stupid person.

Q. Did he manage to make friends?

A. Yes, yes.

Q. So by the time he was at school-leaving age, did he have any qualifications?

A. No.

Q. Or exam results that were able to help him move on?

A. No.

Q. I take it there were many activities as a child that he couldn't do?

A. Yes, well, he wasn't one for, like, football or anything anyway. It was animals, outside, fresh air, animals. No time for football. I don't know if it was because he couldn't do it, I don't know. He absolutely had no time for football. He liked to swim a bit but other than that -- no, outside, fresh air, that was all he ever wanted.

Q. Okay. So you tell us at the top of page 2 that you think that [redacted], when you married in 1964, was using plasma treatment for his haemophilia?
A. Yes.
Q. You remember that you were not long married when he was admitted to hospital for a tooth extraction?
A. Yes.
Q. Sir, some medical records of [redacted] came into the Inquiry office on Wednesday lunchtime, which had unfortunately been filed away in [redacted]'s solicitor's office. So we do now have them and I may refer to a couple of the records and we will lodge them in court book after. But if any issues arise out of them, which I think is unlikely, then we can revisit the documents.
THE CHAIRMAN: Are they in electronic form or paper form?
MS PATRICK: They are in electronic form, so it shouldn't take too long to get them into court book.
But one of the documents that the Inquiry has received was a document showing that [redacted] was admitted to hospital on 9 September 1964 for dental extractions and I'm wondering if this is the episode you are talking about here?
A. It maybe was 10 October. We were married in June and I knew it was not long after that. I knew that. I thought it was October but September/October.

Q. He was kept in hospital until 19 September and received treatment with fresh-frozen plasma. I think in the same records there is record of [redacted] having been admitted to the hospital again about three years later, 1967, for a treatment of a bleed resulting from a fall. Do you remember that?

A. No.

Q. I think he had hurt his knee but please say if you can't remember?

A. I can't (inaudible) but he will have been at the hospital but long before that he is there between those dates, and nine times out of ten, it was his knee.

Q. His knees gave him the most problems?

A. Most times when he haemorrhaged it was his knee. Well, both knees actually.

Q. Okay.

THE CHAIRMAN: I take it he wouldn't always be admitted, sometimes he would just go and be treated and get home?

A. Yes, but once that treatment started to come out, he was going over to the hospital more as well to get the treatment as well.

MS PATRICK: So it seems that [redacted] then received treatment with cryoprecipitate in the 1970s and sometimes treatment with Factor VIII as well, and then medical records, which we have and will lodge, show that in 1981

[redacted] was treated with cryoprecipitate on 32 occasions that year for different types of bleed in the joints and he was treated with cryoprecipitate on 12 occasions in 1982.

Then in 1983 he received a mixture of cryoprecipitate and factor concentrate on 19 different occasions for bleeds in different joints and for dental extractions.

A. Right.

Q. So obviously dental problems brought with them treatment as well?

A. He never ever went with to a local dentist.

Q. Where did he go?

A. The oral, the Edinburgh Royal Infirmary. He always went for his dental treatment. He was never, ever under -- I think the only time he was under a local dentist just before he was taken really with AIDS, and he had to get all this -- he got dentures, and that was going to get the dentures, not to get the treatment at the local dentist. Every time it was the oral surgery at the Royal Infirmary he went to.

Q. Okay. I would like to refer you to a document, WIT0010437, which is a treatment sheet for [redacted] for most of the year of 1984. As you will see from the columns on the left-hand side, this shows treatments

from the 1 January down to 3 October and we can see that the sites of the bleed are recorded in a column, and you have already told us the knees caused him the most problems so unsurprisingly knees are often mentioned?

A. That's right.

Q. The two knees are mentioned frequently there.

Looking down the batch numbers, we can see that the batch numbers are recorded of the treatment which [redacted] received and that between 7 March and 1 August, [redacted] received batch number 90?

A. Right.

Q. Do you recognise this treatment sheet?

A. I have got a copy of that.

Q. You have a copy of it?

A. When I asked for his records, I hardly got anything but this one was in it.

Q. Right. So do you think that's quite a typical example of the bleeds that [redacted] suffered from?

A. Yes.

Q. And the amount of times he needed treatment?

A. Yes, sometimes not as much, sometimes more. You could never put a time on it or an amount on it, that it happened.

Q. Yes. At this time he is obviously just being treated

when a bleed happens?

A. Yes.

Q. Was there a time when he took treatment to prevent bleeds occurring?

A. Not to my knowledge. It was only whenever he felt it coming on or if he had the treatment in the house at that time, take it.

Q. Okay.

A. I never heard him going over and -- I never knew they could do that, go over and take anything to prevent anything.

Q. Right. The records we have seen suggest that [redacted] might have started treating himself at home about this time?

A. Yes.

Q. Does this sound right to you?

A. I would say so, yes.

Q. I'm just wondering if the ‘H’s might suggest home treatment, but you wouldn't be able to remember when exactly he started that?

A. I don't know, I couldn't tell you.

Q. No. When [redacted] treated himself at home with Factor VIII, did he keep records of his treatment?

A. Yes, he did.

Q. Yes?

A. Yes, did he.
Q. Was he very good at that?
A. Yes.
Q. Yes?
A. Yes.
Q. What did he note down? Did he have a specific form from the hospital that he had to compete?
A. I think he just kept the date it happened and the batch numbers and that. He used to write all that down.
Q. And the reason for the bleeds?
A. Yes.
Q. Then what happened to those records?
A. I honestly can't mind.
Q. Right. Going back to your statement, please, to paragraph 5, you tell us that nothing was discussed with [redacted] regarding the risks and benefits of his treatment?
A. No.
Q. You say the only thing he was ever told about was the risk of another hepatitis virus but not the Hepatitis C virus?
A. No.
Q. Or the HIV --
A. I had never heard of Hepatitis C.
Q. What do you think [redacted] would have done if he had known that there were any risks of his treatment?

A. He wouldn't have taken it. He wouldn't have. Do you mean before -- if he knew -- risks like that? No, he would have went back to the old treatment.
Q. Would he?
A. Yes.
Q. I would like to move on to the second part of that paragraph, which is about when you first heard of the HIV virus, and you say that you first heard about it when you were 40 years old and went to Canada?
A. That's correct.
Q. You say there was something in a newspaper there which described how a person with haemophilia had contracted the HIV virus through receiving contaminated blood products?
A. That's correct.
Q. So had you heard about the virus on its own before then?
A. Hepatitis, but the hepatitis -- was it A or B? -- years ago, but never, ever Hepatitis C, no.
Q. Had you heard about HIV before then?
A. No.
Q. No. So the first time you heard about HIV, it was at the same time as you heard that it had --
A. No, at that time when I went to Canada, it was HIV I heard about, not Hepatitis C.
Q. Yes.

A. HIV I heard about not Hepatitis C at that time.
Q. Right.
A. HIV, it was that I found out about.
Q. Because obviously what you heard about there was a person with haemophilia contracting HIV?
A. Yes.
Q. What I was wondering was if before that, you had heard of HIV but not in connection with a person with haemophilia?
A. I think we did but it was supposed to be other people, nothing at all, nothing at all to do with haemophilia, nothing.
Q. Okay. But you might have heard of the virus, of HIV before then?
A. Yes, I'm sure I heard of the virus through the media and things like that.
Q. But this was the first time that you heard there might be a connection?
A. Yes, yes. That's what I have wrote there. I actually cut it out and brought it home and showed it to my husband.
Q. Yes.
A. And he completely dismissed it. Told me it couldn't happen here.
Q. And why did he think that?

A. Because he always was led to believe that Scotland produced their own. It was never -- it was always tested, it wouldn't be infected or anything. He was always led to believe that and he believed that right up to the end, he believed that.
Q. Right. So he believed that all the treatment he was receiving was Scottish?
A. Yes.
Q. Okay. So you were obviously worried about the article?
A. Well, I wouldn't say I was worried, I just thought it was a bit funny, a haemophilic. When I brought it home and showed him, he just completely dismissed it. "It can't happen here, it won't happen to us. We don't get that blood. They sell their blood, they sell their blood and it's contaminated with drug addicts and prisoners. It doesn't happen here." Completely, completely dismissed it.
Q. Okay. Moving on to paragraph 6 of your statement, you say in about 1986 your husband got word from the Haemophilia Society about practising safe sex, and you had been married 20-odd years by that time and couldn't understand why you were being told about this?
A. That's correct.
Q. You then go on to talk about a meeting at Edinburgh Royal Infirmary of people with haemophilia and

DrLudlam.

A. Yes.

Q. I think you are aware that such a meeting took place in 1984?

A. Pardon?

Q. A meeting like the one you are talking about there took place in 1984. So I was wondering if your date of late 1986 --

A. That's right, 1986 -- no, I said 1986 was when my husband went over and asked to be tested.

Q. Right.

A. It was December 1986. My husband went over and asked to be tested.

Q. Which we see in the next paragraph. So do you think this was earlier?

A. Late 1984 that meeting has been, yes, after I came back. That bit's wrong.

Q. Could this have been 1984 --

A. Yes, it could have been.

Q. -- that you are talking about here?

A. Yes.

THE CHAIRMAN: So we get the sequence. You have been in Canada, brought back the --

A. I come back from Canada in July 1984, and maybe late 1984 then. We started getting word about --

THE CHAIRMAN: You clearly wanted to know what the position here was.

A. Yes.

THE CHAIRMAN: So you can say fairly clearly that it would be before the end of the year that the meeting took place?

A. Yes, I would say so, yes.

MS PATRICK: Okay. You say that [redacted] went to the meeting but you didn't go.

A. No, it was only -- that first meeting, to my knowledge it was only the men.

Q. You say:

"The doctors there (I am not sure which doctors were actually at the meeting) were asked if the HIV virus could be transmitted through blood products."

A. Yes.

Q. "The doctors told everyone there not to worry. They were still maintaining that it was coming through the gay community."

A. Yes.

Q. "The doctors said, 'We are only telling you about this virus but it won't affect you'."

A. That's correct.

Q. And [redacted] stood up at the meeting and said:

"Of course it won't affect us. Scotland makes its

own."

A. That's correct.

Q. So that was [redacted] stating his belief that the treatment he was getting was Scottish?

A. Yes.

Q. Then one of the doctors there -- and you are not very sure which doctor -- said:

"No. We have been giving you not home grown stuff."

A. That's correct.

Q. You say there that [redacted] could be volatile and he erupted at this. He told the doctors that they had no business giving them stuff from abroad and asked why he had not been told about this?

A. That's correct.

Q. The doctors said that they could do what they wanted. They said that Scotland had been running low and they had to give the patients something.

A. That's correct.

Q. You say that you know what happened at the meeting because [redacted] told you about it word for word.

A. He was that kind of person. He wanted -- he always wanted to know things himself and he would tell you them. He was just that kind of person. He had to dig and dig and dig until he found the answers, and then he would tell you straight off.

Q. So did he come straight back from the meeting and tell you --
A. Yes, he told me everything that happened at the meeting.
Q. You say that he was very, very angry --
A. Yes.
Q. -- after that meeting. Why was he angry?
A. Because they hadn't -- he wasn't told. They weren't telling him. They were under the impression that nothing was going to happen to them.
Q. That was obviously the first time he heard that he might have been treated with something that wasn't Scottish?
A. Yes.
Q. I wonder if we could move on to paragraph 7, which is just at the bottom of this page. You say that in about December 1986 you went with [redacted] and your son to see Dr Watson, a consultant haematologist at Edinburgh Royal Infirmary?
A. Yes, I was convinced it was Henry Watson. It was December 1986 we went to him and I was convinced it was Dr Henry Watson at that time.
Q. Well, the Inquiry has been made aware that Dr Watson didn't start working at Edinburgh Royal Infirmary until February 1990. So it may have been another doctor?
A. It was definitely December 1986.

Q. Right. Yes, because there is a letter confirming --
A. There is a letter to prove it. Balfour Manson, the lawyers got the letter confirming it from DrLudlam.
THE CHAIRMAN: Ms Patrick, was that when Dr Watson was appointed a consultant haematologist?
MS PATRICK: Yes, he was in Swansea until 1990.
THE CHAIRMAN: I suppose it's possible that you got to know the name "Henry Watson" a bit later and that's what stuck, but you are fairly certain?
A. I was convinced. Maybe I'm entirely wrong.
THE CHAIRMAN: It's not the most important thing.
A. It was definitely December 1986, I know that for a fact.
MS PATRICK: I'll show you the letter you are talking about there, which is WIT0010439. I'm sorry, it's not the most easy to read. I think the paper was grey, which hasn't helped the photocopying.
Can you see this on the screen?
A. I have actually got it in the house anyway. I know.
Q. So you know what it says. It's a letter from lawyers. Was this to you and [redacted]?
A. Yes.
Q. It's the second paragraph that says:
"We have been awaiting a letter from DrLudlam confirming when you were informed of your diagnosis and this has just come to hand. He informs us that your

anti-HIV status was made known to you in approximately December 1986."

A. That's correct.

Q. So going back to your statement in paragraph 7, you tell us that [redacted] had arranged that appointment as he wished for you all to be tested for the HIV virus?

A. That's correct.

Q. Do you know what prompted [redacted] to do that?

A. As I say, with that meeting and then they said nothing was going to happen, but there was more and more and more in the media about HIV. There was more and more coming out about haemophiliacs. They were getting more and more transfers up from the Haemophilia Society. As I tried to say to you, he was that kind of person: things had to go in his mind and the form -- and he has got to find out, and it just come to the point he wanted to find out. And it wasn't for himself, it was because he thought we were going to be -- me and my son was -- he wasn't bothered about himself, it was us. This was what was getting him.

THE CHAIRMAN: Had he been going on about this for a while before the arrangement was made for a meeting?

A. Everything was just coming up. I said, "Slow, just bit by bit". And it was creeping in about more haemophiliacs being infected. He said, "What's going on

here? They have said to us 'Have safe sex'. We have been married for 20-odd years. What are we going to have safe sex for?" Alarm bells just started to ring in his mind and he said, "No, there is something going on here". He was just a very suspicious man, especially about medical matters.

THE CHAIRMAN: Maybe "suspicious" isn't the right term but it is building up inside him.

A. Yes.

THE CHAIRMAN: As information comes out.

A. Inquisitive.

Q. It just reaches a point he has to do something about it?

MS PATRICK: As you have just told us there, he was not so much worried for himself but for you and your son.

A. That's correct.

Q. And you had one son. How old was he at this time?

A. 86, the same -- he was born in 1967.

Q. 19.

A. 19.

Q. And the doctor you saw tried to tell [redacted] that your son didn't need to be tested for the virus but [redacted] insisted and you all gave blood samples for testing.

A. That's correct.

Q. About one or two weeks later [redacted] went back alone to see the doctor for the test results and the doctor said

to him, "Your family is okay, and [redacted] said, "Fine" and the doctor then said to him, "But you are not asking about yourself"?

A. That's correct.

Q. And [redacted] replied that he had assumed when the doctor told him the family was okay that that meant all of you, but he now took it that the doctor hadn't meant that and the doctor said, "You are right, you are HIV positive"?

A. That's correct.

Q. Did [redacted] tell you about this?

A. Whenever he come in the door.Whenever he come home.

Q. How was he when he came home?

A. Upset. Relieved for us. But he was upset. More upset, I would say -- no even knowing what had happened to him was what he hadn't been told. That was really upsetting him.

Q. In paragraph 8 of your statement you refer to a letter, WIT0010438, which is a letter from DrLudlam, and I think was that the letter to you?

A. That come to me in 2003.

Q. Yes. You had obviously been asking him for some information?

A. Yes, I had been wanting his records at first, and this was when I started hearing about -- reading about the Hepatitis C, because up until then I hadn't been told

anything about Hepatitis C. And I was like [redacted], I started to get inquisitive, and I asked for records and I got this letter off DrLudlam.

Q. If we look at the fourth paragraph, it stated that he looked back at [redacted]'s records and found that he was negative for the HIV antibody test on 31 January 1984 and was found to be positive on 29 May 1984, and during that period he was treated exclusively with Scottish national blood transfusion Factor VIII concentrate and it seems highly likely that he became infected from that concentrate. During that period we know, having looked at the treatment sheet, that he was treated with an implicated batch, number 90?

A. Yes, you said that.

THE CHAIRMAN: I have a bit of a worry about this letter. You see it says that he was negative on 31 January 1984 and was found to be positive on 29 May 1984. I don't think he actually could ever have been tested on 31 January 1984. How did you read this letter. What did you understand you were being told?

A. When I read it, to me the -- he has been tested in the January and he was negative, but he has been tested again on the May 1984 and he was positive.

THE CHAIRMAN: That's the way you read it, and I can understand that but it's just possible that what ought

to have been said was that samples taken in these two dates were tested later. It's just possible but you didn't read it that way at all?

A. No.

THE CHAIRMAN: I can understand why you didn't but it's one of these letters that maybe creates more confusion than it solves, but we will be looking to try and find out what actually happened, so don't worry too much about the letter itself.

MS PATRICK: If we go back to paragraph 8 of your statement, you tell us after referring to that letter that [redacted] asked the doctor why he had not been told that he had the HIV virus sooner. Was this at that appointment when he found out that he had the HIV virus?

A. Yes.

Q. So if [redacted] was asking that, he obviously thought that the doctors had known about the virus before and that he was positive for it?

A. Yes.

Q. Do you know why he thought that?

A. Well, by that time -- it was 1986?

Q. Yes.

A. I'm trying to think. He just assumed -- we hadn't got him tested at that -- that they are bound to have known before that. This is not just about that date and

been tested and found there and then that he is HIV positive. He says, "It has no just come from the last time I was at the hospital. I have asked for this test." He said, "They are bound to have known".

Q. So that was why he asked why he hadn't been told sooner?

A. Yes.

Q. The doctor told him that DrLudlam didn't like telling anyone that they were HIV positive and you wouldn't be told about your diagnosis with the virus unless you went and asked about it?

A. That's correct.

Q. He told him that DrLudlam didn't like giving people that kind of news and in relation to the HIV virus, the doctor didn't say much more than that?

A. No.

Q. Other than that it might not develop into full-blown AIDS?

A. Yes, he was told that.

Q. Is this what [redacted] recounted to you when he came back from the meeting?

A. Yes.

Q. You say in paragraph 9 he came home and he came in the door and told you right away. He was glad that you and your son did not have the HIV virus. You say:

"To be truthful, we didn't know much about the virus

other than that it affected gay people."

A. That's correct.

Q. "We had no idea what we were in for."

A. That's correct.

Q. You tell us that he thought that they had known for a while that he had the virus. How did he feel about not having been told the result earlier?

A. Very angry. As I say, again not for himself, it was in case it had infected me. This was his whole, whole thinking. He was never ever bothered about himself; it was in case it affected any of us.

Q. You tell us in paragraph 10 that [redacted] had no idea that he had been tested --

A. No.

Q. -- for the HIV virus prior to the time when he asked --

A. That's correct.

Q. -- for the test. And these tests were carried out by the doctors without his consent and he usually gave blood samples when he attended the haemophiliac clinic. You say, if he had known he had been tested for the virus, he would have asked for you and your son to be tested?

A. That's correct.

Q. You tell us in paragraph 11 that after [redacted] was diagnosed with the HIV virus, you just continued the way

you were doing?

A. Yes.

Q. What was your family life like before [redacted] was diagnosed with the HIV virus? Did [redacted] manage to work?

A. No, very rarely, very rarely.

Q. Was this due to his haemophilia?

A. Yes. Even when he was all right, people wouldn't -- we come from a small village and people -- nine out of ten knew him and they wouldn't have taken him on for insurance point of view. If they knew him -- it's the factories and that, you were provided with what they called at that time a "green card" and then you were classed as disabled. And you wouldn't have been taken on by a lot of places at that time, if he revealed he was a haemophilic. He used to say, "I'm all right, I could do such and such a thing", but nine times out of ten they wouldn't have taken the chance.

THE CHAIRMAN: Disability discrimination just ruled, did it?

A. Never had that in their days, not at that time.

MS PATRICK: Did you work at that time?

A. No.

Q. Was your son living with you at that time?

A. Yes.

Q. And had he left school by then?

A. Yes.

Q. What was he doing?
A. He was -- a cement thing. He has been at they jobs later than that. He is married and that now.
Q. So you say that you just continued the way you were doing?
A. Yes.
Q. You weren't offered any advice, counselling or support?
A. No.
Q. In about 1987 [redacted] was referred to Dr Richardson, a clinical psychologist?
A. That's correct.
Q. After a rocky start you tell us --
A. Very rocky start.
Q. A very rocky start. Do you want to tell us about that?
A. Well, as I have tried to put in that, I don't swear, I have never sworn in my life but my husband was the opposite, very volatile. And at that time, as I say, it was coming out about the gays and everything, and I don't mean any harm to anybody. And when Alison first come there she was exclusively for the gays with for HIV, and when he was introduced to her and told, well, he says, "You are not coming near me". Words to that effect. He told he would have nothing to do with her. But he got over that and Alison herself used to laugh about it later on. She was good to him. She was good

to him.

Q. He saw her quite a lot?

A. Yes.

Q. He found that helpful?

A. Yes.

Q. You say at the end of paragraph 11 that he asked her all the things which could happen to him?

A. Nobody was telling us a thing. We didn't know what -- you know when somebody takes cancer what side effects you can get, things like this. Nobody was telling us what could actually happen. What -- we were sitting there in the dark. And I asked Alison one day and Alison completely told us. She says it could be different things, it could be cancer, it could be brain. Alison went through all of it with us. She said, "I'm not saying you are going to get that". But nobody was telling us that. We were just in the dark, we weren't getting told nothing except for Alison.

Q. You say there that [redacted] spoke to her for a while about suicide?

A. Yes.

Q. Then he got past that idea.

A. But I didn't even know until we started doing this Inquiry that he had started speaking to his brother about it. I didn't even know that he had actually been

to his brother about it as well.

Q. But then you say he got past that idea and that Dr Richardson was very supportive to both of you and you continued to see her after [redacted] died?

A. Yes.

Q. You tell us in paragraph 12 that you do not know what [redacted] was told about the risk of transmission and steps to take to prevent or reduce the possibility of transmission of the virus, but after he was told of his diagnosis he never again had relations with you.

A. That's correct.

Q. And you say you tried to reassure him but he was that paranoid and petrified of infecting you that side of your marriage was over forever.

A. That's correct.

Q. You tell us also that he took to drink for a long time?

A. That's right.

Q. Which, from what we have heard earlier, was not the kind of man [redacted] was?

A. Exactly.

Q. Your son had grown up and you had started going out at weekends sometimes together?

A. That's correct.

Q. And --

A. It was always together, he never went out on his own.

It was always together.

Q. That was good until he was told of his diagnosis with the HIV virus and then he started drinking more whisky?

A. That's correct.

Q. It was very difficult for you to cope with that and you say that this was perhaps [redacted]'s way of coping with his fear and frustration?

A. Yes.

Q. You say that he eventually calmed down and by that time he was getting weaker and he wasn't able to --

A. He wasn't able to go out after that as the time went on.

Q. In paragraph 13 you tell us that the first symptoms of the HIV virus that [redacted] had, that you were aware of, were loss of appetite and loss of weight?

A. Yes.

Q. You think that he had these symptoms for a couple of years before he was diagnosed with the virus?

A. Yes, I think so.

THE CHAIRMAN: Before we go on to the symptoms that you are coming to deal with, you have really given us a conclusion that [redacted]'s life for the period that he was drinking wasn't very good, and you have to suffer the spin-off. I have to try and get a complete picture. Can you give me some sort of impression of what was actually going on? Was he drinking every night of the

week or ...?

A. No, no. As I say, he was never a drinker. When we went out, he would drink and drink and drink and then he would come home and it would be argue, argue, argue.

THE CHAIRMAN: So it affected his mood and his attitude to you, did it?

A. Yes, his personality changed altogether.

THE CHAIRMAN: And you got the brunt of it?

A. I got the brunt of it.

THE CHAIRMAN: Was that over quite a long period of time?

A. Maybe about at least six months, maybe more. Maybe six months in the year, yes.

THE CHAIRMAN: I think the picture is clear enough.

A. It was a long time to me because I was never used to that.

THE CHAIRMAN: Indeed.

A. As I say, at one time if you wanted to go out for a drink, he would just walk away, but when we went out, he would just drink, drink, drink. I realised what it was. It was his way of coping with it. But he didn't realise everybody else was getting the brunt of it.

THE CHAIRMAN: I think that's probably enough to fill in the picture.

MS PATRICK: Okay.

THE CHAIRMAN: You do understand that it helps the Inquiry

to know more rather than less but --

A. I mean for somebody that never acted like that, it's a terrible thing to see, that their personality changing like that. And completely going down that other road and being -- even "nasty" is not the word for it. It is more than nasty. You have to try and think to yourself, "Well, that's not him". You are trying to convince yourself.

It wasn't easy and it wasn't easy for my son to be in the middle of it. My son was still in the house at the time, as you know, and he tried to give his dad the benefit as well, but it's hard when your family is in the middle of it as well. He didn't want to see me hurting but he didn't want to hurt his father as well.

MS PATRICK: Thank you. We were looking at paragraph 13 of your statement and you just mentioned that you thought [redacted] had had symptoms of loss of appetite and loss of weight before he found out that he had HIV.

A. Yes.

Q. I wonder if I could refer you to WIT0040144.

Sir, we tried to recover medical records from the health board. There is a letter, WIT0040143, which explained that they were unable to release them as they unfortunately couldn't be located but what was provided was this data stored on a historical database. There

was another page of it.

THE CHAIRMAN: I hope so because this page is not telling me much.

MS PATRICK: It's not telling you very much at all but for what it's worth, it's here and I just wanted to refer to the reference of "PGL" in August 1985, which I wonder if might refer to persistent generalised lymphadenopathy, which is swollen lymph nodes.

A. Pardon?

Q. PGL may be persistent generalised lymphadenopathy, which is swollen lymph nodes.

A. That's right.

Q. Which is one of the symptoms of the HIV virus?

A. Right.

Q. So that's why that's there.

THE CHAIRMAN: Do you remember hearing [redacted] talk about that, lymphadenopathy? He wouldn't get the rest of it.

A. I wouldn't have known the name, but I mind him saying when he started to go -- when he started to feel ill and they were testing him for in here and that. I minded that now. Your lymph glands are in there -- that's right.

MS PATRICK: We were wondering, sir, if the CDC column is the grading of the symptoms in terms of CDC.

THE CHAIRMAN: That won't mean much to you either?

A. It doesn't.
THE CHAIRMAN: CDC, I think, is an American --
A. Actually, I have got a letter from DrLudlam saying that they have not got any record -- his records from 1985, 1986 and 1987. And in his opinion [redacted] wasn't at the hospital and being treated.
THE CHAIRMAN: Yes, well, I think, if we start at the bottom and work up, it's fairly clear that he was being seen and that he has to have been tested in some way for a CDC score to be in.
A. That's correct. Even taken -- even -- they are saying that by this time he was diagnosed with HIV. So was he not getting treated then if there were no records for him?
THE CHAIRMAN: If we just look at this sheet, it looks as if in the beginning of August 1985, information has been available that led to the comment about his lymph glands being --
A. I never got no records for those dates.
THE CHAIRMAN: And no one has told you anything about this sheet yet? Is this the first time you are seeing it?
A. No, I got this just from the Inquiry --
THE CHAIRMAN: Yes, I know. Sorry, in the context of the Inquiry.
A. Not from the hospital or anybody, no. They have got

this, no.

THE CHAIRMAN: I'm sure Ms Patrick --

A. I've got a letter from DrLudlam stating, when I asked why I never got all these record, he says 1985, 1986 and 1978, they couldn't get them.

MS PATRICK: Do you want me to show you the letter?

A. Yes, please.

Q. It was the one we looked at before, WIT0010438.

THE CHAIRMAN: I'm sure if Ms Patrick can help you understand any of it, she will do it so that you get some information now.

MS PATRICK: I think this is what you are explaining here, Elaine. It's in relation to the third paragraph, because you are wanting [redacted]'s treatment records. Yes, and in the third paragraph DrLudlam is saying there that he didn't have any treatment in those years and therefore there would not be any transfusion records available.

A. That's correct.

Q. You talk about that in paragraph 20 of your statement, where you say basically there is no way that you feel that he didn't have treatment in those three years?

A. Plus -- they are saying that he was diagnosed in 1984 with HIV, so was he not getting treatment for that HIV for those three years, never mind the haemophilia?

Q. I think this is in relation to the treatment records for haemophilia?
A. Yes.
Q. Yes. Because I think you felt that they were missing from the records that you did recover?
A. Yes.
Q. Is that right? That is the explanation that you got from DrLudlam for that?
A. Yes. You have already seen the draft for 84, when he had been at the hospital for his haemophilia for the January to the October, 22 times, and then DrLudlam saying he wasn't there for the next three years. It was a big jump.
Q. Could I take you to the next page of the data records that we were looking at, which has a bit more information on it than that page did, WIT0040154. This tells us a bit more and that in April 1989 the entry is irregular pentamidine, which I hope Professor James will know, is a treatment for PCP, the pneumonia?
A. I heard about pneumonia two or three times.
Q. So it's suggesting maybe that he was getting some irregular treatment of that drug to try and prevent pneumonia.
A. I know at least twice he had that pneumonia.

Q. He does have that because we can see that further up on the sheet -- it actually goes up in time -- you will see that along the line from 1 June 1990, it says "PCP", which I think is referring to pneumocystis pneumonia?
A. That's correct, yes.
Q. "Start AZT ..."
Which is treatment for HIV:
"... and PCP prophylaxis."
Which is suggesting that he carries on taking a medication to stop PCP, the pneumonia, coming back. Because you tell us that in paragraph 13 of your statement -- you don't need to go back to it -- that in about 1988/1989 [redacted] developed pneumonia.
A. Yes.
Q. But could it have been June 1990, as shown here?
A. Yes, that's what I'm saying, I wasn't sure about the dates. I found out that right date. It was June 1990.
Q. Yes. It is quite a wee way back. So don't worry about that.
THE CHAIRMAN: You think 1989 and if we look at 1 April 1989, [redacted] was getting Pentamidine, which is related to that disease. Do you remember if he did have lung-type problems, shortness of breath, things like that?
A. Yes, I think he did. Yes.

THE CHAIRMAN: There had to have been something that would spark off treatment.

A. As I say, I just can't remember -- go through everything. What was it? It was a lack of appetite to begin with and then everything just kept coming on with that, and then he lost the weight and he did start getting a bit chesty, things like that, and then I can't mind the first time he attended with pneumonia the first time, because they said at that time, when he had taken the pneumonia the first time he was kind of lucky, because to begin with, maybe a few years before it, you only got that pneumonia once and you usually died not long after that, but they cured him of it. Well, they got it. It must have been about June 1989, he had taken it again. I just can't mind when it was the first time he actually took the pneumonia.

THE CHAIRMAN: Perhaps it doesn't matter terribly much, but if we take it that there must have been some symptoms earlier.

A. He has had this before that. So he has obviously had the chest problems and that as well.

Q. In paragraph 13 you tell us that he developed pneumonia, and it may be this June 1990 time?

A. I know there wasn't much time between them when he had the pneumonias then.

Q. This suggests it could have been June 1990 and January 1991?
A. That's what I'm saying. I knew it wasn't long between them. He seemed to be just getting over it and he was getting it again.
Q. Yes. Can you remember if it was the first or the second time that [redacted] had the pneumonia that he was told that he developed AIDS?
A. It was the last time.
Q. It was the last time?
A. It was the last time he had pneumonia, yes.
Q. You tell us that he was in hospital and Dr Watson was by then at Edinburgh Royal Infirmary?
A. Yes.
Q. He told [redacted] that he had developed full-blown AIDS and tested him for this and he told him that he would come back and give him the results of that test?
A. He told him -- he was saying to him it was pneumonia and he was going to be testing him for full-blown AIDS, and he would come back. [redacted] said, "Will you come back and tell me the result," and he said "yes", but he didn't. It was another young doctor.
Q. [redacted] said that the doctor just said he was in for full-blown AIDS and walked out of the room, and [redacted] was very upset to have been told the news that he had

AIDS --

A. They said to him it was that type of pneumonia and that means you are in the full-blown AIDS, and he just walked out the room again.

Q. [redacted] later got an apology from Dr Watson for not having been told.

A. Yes, he did.

Q. You tell us that [redacted] then did have pneumonia two or three more times, you say, and his body started to give out and he had to have a nasogastric tube inserted?

A. Yes.

Q. This is at the bottom of paragraph 13. He had a lot of infections.

Sorry, I wonder if we could just go back to that form we were looking at, just so we could finish off what it told us. 0145. This also tells us that [redacted] started AZT treatment, which was treatment for the HIV virus, in June 1990. How did [redacted] find that treatment? Did he have any side effects from it?

A. I don't know if -- I don't know if it was thought there were side effects of the treatment or was it the effects of the actual virus. He had a lot of diarrhoea. His face was always covered. It was things like that. Tired all the time. I don't know -- we just took it to be the actual virus.

Q. So his AZT was increased in January 1991 and it's noted that he is on Pentamidine, which is this drug we were explaining that is to try to prevent the pneumonia happening.

A. Right.

Q. Then it's recorded, April 1991, "HIV wasting", losing weight, which you have described to us already. Then in July 1991, oesophageal candidiasis, which is an infection?

PROFESSOR JAMES: Fungus infection.

A. Like thrush and that you mean?

PROFESSOR JAMES: It is thrush, absolutely right. That's what it is.

MS PATRICK: Do you remember that?

A. That's right.

Q. Then in November 1991 he stopped AZT and it's noted cytopenia, which is I think is a reduction in the number of blood cells. Could that have been the side effect?

PROFESSOR JAMES: Yes.

MS PATRICK: So maybe he stopped the AZT there because he was having bad side effects, which was cytopenia. Then in December 1991, he restarted AZT treatment.

You say, going back to paragraph 13 of your statement, that you became his carer and did everything for him?

A. Yes.
Q. He had a nasogastric tube inserted?
A. Yes.
Q. Did you help with feeding him?
A. Yes.
Q. Through that tube?
A. Yes.
Q. Presumably, as his condition deteriorated, more and more of your input was needed to look after him?
A. Yes.
Q. What support did you get during that time?
A. The local doctor -- as I say, the only support was when Alison came out. My local doctor would come out and the nurse -- the local nurse came Monday. That was maybe [redacted]'s fault in one way. He was that kind of man. He said, "I don't need help, my wife will do it". I had nobody from the hospital or anything. The only help -- it was Alison come out, give us advice and my doctor was there if I needed anything. That was it.
Q. Did your son help too?
A. I didn't ask my son. My son would do -- my son is a very deep person. And I would even help [redacted] in the bath and everything. He was complaining one night I was going to give him pneumonia. He was not going to die with the HIV, he was going to die from the pneumonia.

Because this new chair to try and get him in -- we didn't have a shower, we had to get a shower later on -- and I'm trying to get him on the chair in the bath and he is saying, "Would you get the water on, I'm going to die of pneumonia, not the HIV". Those things, you had to kind of laugh, or you would just break down. So I nearly killed him with pneumonia by not bathing him right. I done everything for him, everything.

MS PATRICK: Which was obviously exactly how he wanted it to be.

A. Yes, that's how I wanted it as well.

Q. In paragraph 14 of your statement you tell us how you didn't know how to tell people about his diagnosis?

A. Hm-mm.

Q. You tell us that you didn't tell many people?

A. That's right.

Q. Who did you tell at the time that [redacted] was diagnosed?

A. There was a person we used to go to when we went out to have a drink, and that was a person he went out -- and he told this person, and nothing was said that night but later on, a couple of weeks later, it was New Year, and we had been at their house and he came over to [redacted] and he said, "Don't you kiss my grandchild again", and [redacted] just went home and completely broke down. It broke his heart. For a start he loved children. He would never

hurt a child in his life and that just...

Alison used to say that. She said, "I don't know how you are with that. You are in a small village. I don't know if it will work for you or it will work against you. If people know, they might rally around you, lend a hand, and everybody would know then." You didn't know what to do.

Later on, I don't bother now. [redacted] never done any harm now. And more people know now -- especially the fact that -- [redacted] comes from a big family, same thing in a small village, every second person is a (inaudible), and that's true. And I let them all go daft now, say, "Why did you not tell us?" But we didn't know how people would react and after he done that -- and it wasn't for himself. He didn't want my son -- my son was at that age. He didn't want anything coming back on my son.

My son was -- it's his wife. My son was going with a girl at that time. He didn't know how she would react. You have to look at all that kind of thing. She is his wife now, I have got two wee grandchildren now. So it worked out that way but after the boy done that to him he just -- he didn't want to tell anybody else.

Q. You can understand why he took that view. You tell us also that he became good friends with a 30-year old boy

with haemophilia who had acquired the HIV virus and sadly this boy died a couple of months before [redacted] and that broke [redacted]'s heart. You tell us that in January 1992, it was the only time that [redacted] broke down about his condition. So he had obviously been very strong and he had been to the hospital and had told the nurses there that he thought he only had six weeks to live?

A. That's right.

Q. They had told him not to speak like that and he had perhaps a year, and [redacted] came home and told you about this and you told him that he promised you he would keep fighting, and he said he would keep fighting but he was tired.

A. He came home that day and he broke down. I said to him, "What's wrong with you?" and he said, "I've been told today I have only got six weeks to live". I said to him, "Nobody can tell you that." He said -- it turned out they hadn't told him that but that boy dying, that finished it. And he was upset about that and he says what he had actually said, "I will be the next. I have only got about six weeks", and they said to him, "No, [redacted], you haven't, you have got at least another year".

And he was spot on, he. Only lasted another six weeks and that's when I says to him, "You promised me

you wouldn't give in". And looking back, I said why did I say that because he says, "I'm not giving in," he says "I'm tired," he says, "I'm tired". And I will never forget him saying that.

Q. As you said, [redacted] died sadly about five weeks later on 8 February 1992, and he died at home?

A. Yes.

Q. He had asked the doctors not to put AIDS on his death certificate?

A. Yes.

Q. So that lists the cause of his death -- this is in paragraph 15 -- as septicemia, pneumonia, immunosuppression and haemophilia.

You tells us that you were tested for HIV yourself about a year later.

A. Yes, I. Had to go into the hospital myself for a minor operation and I says to my own doctor, "I would like to be tested". She said I have already been tested and I said, "But that was before [redacted] died". I said, "Look, I want to be tested again. Nothing has happened but I don't want to go into a hospital -- I have had it done to me. There is no way in this world I would go into a hospital not knowing for certain." And I went and got the HIV test again myself and it was negative.

Q. Right.

A. That would be about 1992/1993, something like that.
Q. In paragraph 16 you tell us about what happened to [redacted] just after he died. I wonder if you could tell us about this, please?
A. As I say, when my husband died -- my husband was that kind of person. He was from the old school. He always says, when he died he would be kept in the house. He was cremated. He always wanted cremated anyway.
I said, "All right." And he died that night, and as I told you, it's a small village, it was an old, old undertaker we had, and he come. He was sorting him out. And he is saying, "I'll sort him and everything", and I said, "I had better tell him". So I told the undertaker about [redacted]'s HIV and he just tied everything up. He said, "I can't do anything more. I can't sort him. He has to be taken away". And my son was the one -- with my brother-in-law -- that put my husband in a body bag to take him out the house. And to this day nobody has told me where my husband went to.
I don't know where they took my husband. When -- Alison actually phoned that day and I says to her, "They have taken them away". All she says to me that day, "I thought you understood they would have to take him away". But nobody still says to me where. And then my cousin come up and she was actually on the phone to my

undertaker saying, "Look, where is he? Let her go and see him". They said, "It will not be any good. She won't get to see him". And to this day nobody has told me where they took my husband. It was my son at that age who put his father in a body bag to take him out the door.

Q. Are you okay to carry on?

Following on from that in paragraph 17 you tell us that you feel very upset and angry at the way your husband was treated.

A. Yes.

Q. And you tell us also that you received treatment for depression for a few years after he died and as you will be aware, your general practitioner has provided a report, which I think you have seen, which is WIT0040704. This is a report by one of the GPs in your GP practice.

A. Yes, that's right.

Q. The GP who writes this didn't personally meet you until December 2004?

A. Yes, and the doctor was actually there when my husband died. She is retired or in another practice now. It has all changed round about.

Q. So the majority of this report is taken from entries in your medical notes and it says that in 1987 you were

diagnosed with anxiety, depression and on 18 May 1990 you were treated for anxiety. On 10 February 1992, you were visited for bereavement and on 9 March 1992 reactive depression was diagnosed. This appears to have persisted and you received medical certificates stating you were unfit for work from 10 February 1992 until at least 1998. And during 1992, you attended a counselor/ psychologist, but you didn't wish any medication at that time?

A. No, I tried to work through it at times myself, rather than take medication. I try and not be dependent on pills. And a lot of times I try and just work myself through it, but at sometimes I can't. And my doctor realised that. She knows when I go up, I need it at that time. A lot of time I just try and work through it myself. I don't want to be dependent on it.

Q. It says that about your HIV test, which was negative on 5 July 1993. It was documented that you felt guilty about this. I think since you have seen this, you have told us that that should read "Why not me?"

A. That's correct. I felt guilty that I wasn't -- I did not have it. Why did [redacted] have it and why did I escape? I felt guilty.

Q. Over the page it tells us that from this time onwards you were seen on a fairly regular basis and

received a variety of different antidepressants, which you took and then you discontinued after some time. In August 1998 you were verging on panic attacks?

A. Yes.

Q. In August 2000 you were concerned about Hepatitis C infection and you have been tested for that.

A. Yes.

Q. Thankfully this was negative.

A. Yes, I asked for the test myself, the Hepatitis C test. At my local doctor.

Q. Yes. Because I think you found out that [redacted] had had Hepatitis C but after he died?

A. No, I didn't know he had Hepatitis C until 2003.

Q. Yes.

A. I wasn't told -- I was told nothing about Hepatitis C. I didn't know -- I had seen DrLudlam in 2003. That was the first time I had known -- 11 or 12 years after [redacted] had died -- about Hepatitis C.

Q. The test result for that, which we don't need to look at, is WIT0010440, for Hepatitis C virus.

THE CHAIRMAN: The date?

MS PATRICK: I will tell you. If you would like to have a look at it.

THE CHAIRMAN: No, just give me the date.

MS PATRICK: Date reported January 1992.

THE CHAIRMAN: Did [redacted] never say anything to you about Hepatitis C?

A. No.

THE CHAIRMAN: He doesn't sound to me to be the sort of man who would have kept things from you.

A. That's what I'm trying to explain to people. I know for a fact, I'm 200 per cent sure -- I mean [redacted] come home and told me about the HIV. If he knew there were anything wrong with Hepatitis C as well -- not for himself again, for me -- I would have definitely been told, and I can -- 200 per cent, I can tell you that for a fact.

THE CHAIRMAN: Because January 1992 is very near the time he died. It's very late on.

A. But why was I not told myself by a doctor then?

THE CHAIRMAN: Maybe he wasn't told in the circumstances, I don't know.

A. Sorry, who wasn't told?

THE CHAIRMAN: Maybe [redacted] wasn't told.

A. I know for a fact [redacted] wasn't told, because he would have told me. Why was -- why did I have to ask again? Why did I have to go through -- and go for the test myself again? This is the answers I'm wanting. That's 12 years. I have to go and go through -- go to my own doctor and ask for a test, go to DrLudlam and ask if

[redacted] -- I asked DrLudlam, "Why did you not tell? Why not even me?" And I have not got proof. I was by myself with DrLudlam. His answer to me was partners are not at risk. Hepatitis C is not through -- through sex and families, as through needles and transfusions. That's what he told me in 2003. That's not true. I mean, I could have had Hepatitis C all these years.

THE CHAIRMAN: Yes.

MS PATRICK: Sir, that's recorded in paragraph 19 of the main statement, for your reference.

Going back to your GP's report, it states that the 10th anniversary of [redacted]'s death in February 2002 prompted another spell of antidepressant therapy and you continued on treatment intermittently from then:

"In June 2007, the inquiry into her husband's death from HIV prompted a further spell of depression, again requiring antidepressant medication."

What Inquiry was that?

A. That must have been when I started hearing about the -- that was when the Inquiry was coming up and you were starting to hear all the different stories and this --

Q. Brought it all back?

A. Yes. When I've hit my head up against a brick wall.

Q. The last evidence of antidepressant medication being prescribed is 2 February 2009, some 17 years after [redacted]

died.

Paragraph 18 of your statement, which is WIT00400052, you tell us that in 1990 [redacted] was advised by his GP to claim for special attendance allowance?

A. That's correct.

Q. You tell us there about the difficulties despite the GP supporting the application, that it took it being completed on three separate occasions, visiting your MP and being medically examined by an Edinburgh-based GP whilst he was in hospital before his claim for this allowance was granted --

A. When they finally -- Geraldine Brown -- and she finally phoned me to say they had finally received word. They had finally admitted. And she says, "But I have got good news and bad news", and I said, "Why", and she says, "Because he has got to have a medical". And that was the day -- I had just got him home with the gastric to feed him, and I remember he had to stand that day and I had him hooked on to the wall to feed him. And I said, "There is a doctor to come out." I said, "Just forget it. I don't want their money." She said, "No, it will be somebody from your own practice that will come out and give him a medical". I says, "You are joking," she says, "I'm not".

It was not my actual practice. It was another village next to me. By the time the doctor phoned a couple of weeks later, [redacted] had been taken back to hospital with pneumonia again. But they ended up sending a local Edinburgh doctor from Edinburgh Royal Infirmary. They gave him a medical for that attendance allowance.

Q. You tell us also that while [redacted] was alive -- this is about the bottom third -- he received money from the Macfarlane Trust?

A. Yes.

Q. You received £1,000 when he died?

A. That's correct.

Q. At the same time the trust wrote to you and said that, as you had no dependents, your son being grown up, I take it, you would only receive the widow's allowance for six months. But after you wrote to them, they continued to pay you £80 a month and then £100 a month. And they wrote to you in 2009 to say the money was running low and they would need to stop payments to widows and widowers, but at the time of your statement that hadn't happened?

A. They have actually got more money now. They actually got more money last year, and the truth about that, I have actually got more money now. I don't know if it

was the Government or not, but up to the end they were ready for cutting a lot of people off at that time.

Q. Sorry, could you bear with me a minute? Thank you.

(Pause)

THE CHAIRMAN: Ms Patrick, the stenographer wants a short break anyway.

MS PATRICK: Okay.

THE CHAIRMAN: You can work things out with Ms Dunlop. We will have a short break.

(3.17 pm)

(Short break)

(3.22 pm)

THE CHAIRMAN: Yes?

MS PATRICK: Thank you. Elaine, there are a couple of points that we thought might be helpful for Professor James, the medical adviser to the Inquiry, to assist us with. The first of these is what treatment was available for [redacted] for his HIV because it seemed that you were a bit anxious that he didn't get treatment until 1987.

A. He didn't get treatment until 1987.

Q. Yes.

A. I never had any records about what he was getting, that's correct.

Q. So I was going to ask Professor James to explain to you

about when AZT became available.

A. All right.

PROFESSOR JAMES: Are you happy with that Elaine?

A. Yes.

PROFESSOR JAMES: So it looks from those records as if [redacted] did attend the clinic several times in 1985 and 1986 and from what we can make of those -- as you saw almost like a computer record -- it appeared that they knew that he had HIV, and they were monitoring him quite carefully to see if he had any bad symptoms at that time.

The records suggest that actually he was in pretty reasonably good health during 1985 and 1986. So, number one, if any treatment for more advanced HIV moving towards things to do with AIDS had been then, then they would have been in a position to give it to him but he didn't need it. That's number one.

But more important, the Inquiry has been told by an expert that the AZT treatment actually wasn't available anywhere in the world until 1987. So as a matter of fact, he didn't miss out on some treatment because there was no treatment until 1987, and he started to get ill, as you know, shortly after that really and he, in my view, having seen the computer records, got very good and appropriate treatment at that time.

There was no kind of prevention treatment in 1985

and 1986. There is now but this is 25 years later. So I really don't think he missed out on any treatment that he should have had that would stopped him getting what became AIDS or would have saved his life, to be honest.

That's the first thing.

THE CHAIRMAN: Is that helpful to you to know?

A. Yes.

THE CHAIRMAN: You are still -- you have got your doubts?

A. No, you are saying that he was getting tested in 1985?

PROFESSOR JAMES: I'm saying that they knew the result of the test actually, probably -- we are not certain -- right at the end of 1984. They knew the result of the test. So the meaning of that letter from DrLudlam was that they had saved up blood samples, which they did for loads of the haemophiliac patients, and they sent them all off for testing and when it first became available, what they found was that [redacted] had been negative from a blood sample that they, if you like, had in the fridge from when he had attended the clinic at the very beginning of 1984. But from another blood sample in June 1984, which they only had tested probably in about November 1984, actually it turned out that he was positive.

It wouldn't be appropriate for me to comment on why he wasn't told at that time or anything like that.

A. That's my question. That's my question.
PROFESSOR JAMES: That's part of the Inquiry. So it's not fair for me to make any remarks.
A. No, I just want to establish they were testing him at that time?
PROFESSOR JAMES: The first time there was a test available was probably about November/December, but they had samples of his blood stored in the fridge, which loads of people had. And it wasn't for anything bad, it wasn't for experiments for anything like that. So when a test became available, they said for all the haemophiliacs all over Britain, "We have got these samples in the fridge. Let's test them and see if our patients might be positive because we ought to know that so we can monitor them and see what happens or if they are still negative."

He probably turned out -- we are not certain -- to be positive at that time. Then what we have seen from those records is that they did take quite lot of care in seeing whether he had anything that made them suspicious that he was going on to get very ill, and for those two years, 1985 and 1986, nothing terrible was going on. Anyway, there was no treatment. The first treatment, the AZT treatment, available anywhere, was in 1987 and that's around the time that he started to get ill, and

actually he started to get correct treatment for the things that he was ill with.

I don't think there is any real doubt about that. I don't think anything bad has been done there.

THE CHAIRMAN: Except you don't think he was told.

PROFESSOR JAMES: That's a different matter and I can't comment on that.

A. Right you are.

MS PATRICK: The second matter I was going to ask Professor James to help us with was in relation to Hepatitis C. It was obviously a great concern to you that you didn't know that [redacted] had Hepatitis C.

A. Correct.

Q. And you feel that you were at risk of infection of Hepatitis C from him?

A. That's correct.

Q. So Professor James is going to explain --

PROFESSOR JAMES: I'm on surer ground now because I'm a liver expert, so I know about hepatitis.

It's quite right that Hepatitis C is much, much, much, more commonly transmitted by needles -- and this is part of this query -- transmitted by infected blood in blood transfusions. Again, there was no test for Hepatitis C before around about 1990. That's the sort of time when the test first came in.

So that's number 1. Number 2 is that it's very, very uncommon for the partner or spouse of a person with Hepatitis C to be infected by the partner or spouse by sex. It does happen but it's as rare as hen's teeth. It's very, very uncommon. So in my view, it's not really surprising that it was not thought necessary for you to be told that your husband had had Hepatitis C. And, remember, the first time they appear to have tested him was a few weeks before he died, when obviously everybody was concerned with the fact that he was dying effectively of AIDS with all the terrible, terrible story that you have so well and clearly told to us.

So honestly, I wouldn't blame a hospital specialist in any circumstances, however it had arisen, for not saying to the wife of the person, "Your husband had Hepatitis C. You should get tested."

In an ideal world, maybe they should have said to you but to be honest, it's not a big issue. And it's easy for me to say this but if I was you, I wouldn't kind of go on worrying and ruminating about it. In a sense, that's the least of your worries in my opinion. It's very uncommon, very, very uncommon.

A. But it has happened.

PROFESSOR JAMES: It certainly has.

A. If there is one bit of doubt -- no, I don't think --

PROFESSOR JAMES: I can't answer the question.
A. Why was I not told?
PROFESSOR JAMES: I can't answer the question of why you weren't told. Again, you may be sure that Lord Penrose will look into that and that's why everybody is here, you included. There will be a great part of the Inquiry dealing with Hepatitis C and people who got it and so on. You are quite right, there are family members of people who were infected with Hepatitis C who did get it. All I'm saying to you is it is very uncommon, one in 500 or something like that, not very likely at all.
THE CHAIRMAN: So that's Professor James's advice to me as well as to you. But I think you can leave here with any help you get from that, but you can be sure that I will be asking these questions about why not and you will get to know if we can find out in due course. Is that all right?
A. Thank you.
MS PATRICK: I just have a couple more questions for you Elaine. The first of these is how did [redacted]'s illness and death affect your son?
A. My son still doesn't -- my son is a very deep person and -- actually, when this Inquiry started to come about -- my son goes out and has a drink, he likes to go out, and he had had a drink one night and he says to me,

"Forget it all. Don't go near the lawyers. Don't go near anybody, forget it." He just wanted it all out of his mind. I said, "No, I'm not forgetting it". But then a couple of weeks ago he says, "Mum, if you need any help, just tell me and I'll come with you". He is a very, very deep person, very deep and he just -- I still say that has affected him as well, that day he had to do that for his father. I don't think it has ever left.

[redacted] died on the February and my son -- a couple of weeks after he died my son come to me and he said, "I'm going to do what my dad asked me to do". [redacted] took him aside -- when my husband died [redacted] did everything. He told had him -- as I told you, he was that kind of man. Everything was sorted out. [redacted] -- I never done a thing, [redacted] done everything.

Then a couple of weeks later he comes to me and says, "I'm going to do so what my dad asked of me". He said, "I'm going to get married". He had got a house in the November. He said "Well, you'd better get married, mind, you just got a house". And he come and says to me -- and he said, "I'm going to do it", and they got married in the May. And I still say what he done with his dad that day -- putting him in a body bag -- has really, really affected him. Because about a year

after, his wife came to me and she says, "I'm having problems with him and he will not talk to me at times", and she said, "I think it's a lot to do with this". He went through that as well.

As I say, a couple of weeks ago. Maybe if you need any help now ... But it has taken him a long time.

Q. And lastly, how do you feel that [redacted]'s illness and death have affected you beyond what we have already seen?

A. Just -- I will never get over it. Never, never. I have just not got the words. Just tried to explain it on the thing I gave you.

Q. Yes. Well, thank you very much for that. It has been very good of you to come here today and to tell us about [redacted] and what happened. Thank you very much.

THE CHAIRMAN: Mr Di Rollo, are you content?

MR DI ROLLO: Yes. Again, just to thank the lady very much for coming and giving her evidence.

THE CHAIRMAN: We can be sure that we will be trying to tell your story in due course and if possible answer those questions that are still outstanding.

Thanks for coming.

A. Thank you.

MS PATRICK: That concludes today.

THE CHAIRMAN: That concludes today, and we come back on

Tuesday?

MS PATRICK: That's correct, sir.

THE CHAIRMAN: I hope that everyone can have a better weekend than we have had a week.

(3.43 pm)

(The Inquiry adjourned until Tuesday 14 June 2011 at 9.30 am)

I N D E X