Thursday, 25th February 2021

(10.00 am)

SIR BRIAN LANGSTAFF: Good morning, Ms Hithersay. Can you hear me?

THE WITNESS: I can't hear you. *(Pause)*

SIR BRIAN LANGSTAFF: You're talking to a room which has three lawyers facing me. There are three members of the Inquiry staff, one of whom is Mary, who will ask you to take the oath in a moment or two, and then we have Soumik, whose job it is to make sure that when documents are referred to, you see them on your screen until they're taken down, and you will see Ms Scott again. Ms Scott will be asking you the questions.

Beyond the Inquiry room, there will somewhere in the region of 200 people watching on either YouTube or Zoom, and they will hear what you have to say as if they were here which, because of current restrictions, plainly, they cannot be.

So that's the scene. First of all, you'll be sworn.

ANN HITHERSAY (sworn)

Questions by MS SCOTT

MS SCOTT: Ms Hithersay, can you hear and see me?

A. I can.

Q. Thank you. You took up your role as administrator for the Macfarlane Trust in September 1987; is that right?

in October 2003; is that correct?

A. That is correct, yes.

Q. Your role both in the Macfarlane Trust and the Eileen Trust was taken over by Martin Harvey in October 2003?

A. That is right, yes.

Q. In that same month, October 2003, you became a trustee of The Haemophilia Society and you remained a trustee of The Haemophilia Society until December 2010 when you stood down and you didn't seek reappointment; is that also correct?

A. It is not quite correct because, having seen the papers and been reminded of becoming a trustee of the Society, I see that, in fact, I attended an extraordinary meeting of the board in September 2003, and that was not in my statement because it is not what I recalled.

Q. You're there talking about The Haemophilia Society, yes?

A. I am talking about The Haemophilia Society.

Q. So at the point you became -- I will refer to you as the chief executive -- the chief executive of the Macfarlane Trust and the Eileen Trust, your statement tells us you had had experience in the charitable sector, having been employed both as a regional director for the charity Scope, and also having been a director of the Saint Christopher Fellowship, and in that latter role you'd

A. That is right, yes.

Q. At some point over your tenure there, the title of your role changed from administrator to chief executive. But is it right in understanding that your job remained the same, although the title had changed?

A. Yes, my job remained the same.

Q. When you arrived at the Macfarlane Trust you were told that part of your role was also to act as the secretary for the Eileen Trust. Is it right that you hadn't known about that until you took up your position?

A. That is correct.

Q. You were taking over from Wing Commander John Williams who had been both the administrator for the Macfarlane Trust and the secretary for the Eileen Trust since both of those organisations had started; is that right?

A. That is right, yes.

Q. The chair of both the Macfarlane Trust and the Eileen Trust trustees was the Reverend Alan Tanner?

A. Yes.

Q. Is it right that he remained the chair of both boards of those trusts until he was replaced by Peter Stevens in March 2000?

A. That's right, yes.

Q. You continued as chief executive of the Macfarlane Trust and secretary of the Eileen Trust until your retirement

been responsible for managing children's homes and special needs housing; is that correct?

A. That is correct.

Q. And that you had also taken and obtained a master's degree in business administration.

A. Yes, that's correct.

Q. So was your role at the Macfarlane and the Eileen Trust, was that a move sideways or was it a career progression from the roles that you'd undertaken previously?

A. I don't think I really considered at the time. I left Saint Christopher's Fellowship and obviously looked for more employment, saw the advertisement, or -- the post was actually advertised as director of the Macfarlane Trust and it didn't include anything about the Eileen Trust in the advertisement.

Q. How would you describe the responsibilities and duties of your roles within the Macfarlane Trust and Eileen Trust as the chief executive or director?

A. I was responsible to the board of trustees and for the management of the staff team, and for ensuring that the aims and objectives contained in the Macfarlane Trust, Eileen Trust, trustees -- trust deeds were carried out as far as I was able, in accordance with the direction and guidance of the trustees.

Q. So is this right: were decisions made by the board that

you, as chief executive, had to implement with your staff team?

A. That's right.

There were some decisions that were delegated to the staff team.

Q. As we go on through the morning, we'll look in a little bit more detail at some of those.

Did you also have a role as chief executive in advising the board on policy, on strategy, and on the decisions that they were required to make?

A. I certainly advised them of what the staff and I myself gleaned, picked up, if you like, from our information, our communication with the registrants of both trusts.

Q. So part of your role was liaising with the registrants and feeding that into the board?

A. Yes.

Q. But in terms of policy and strategy and decision-making that sat with the board, given your experience in the charitable sector and given that the trustees were unpaid volunteers, is it not right to understand that the chief executive did have an advisory role, advise the board about strategy and policy and so on?

A. I certainly think that with the original chair and vice chairman of the Macfarlane Trust, there wouldn't have been any question of my attempting to advise them on

policy and strategy matters. I hope that when the next chairman took over we probably had more dialogue but, again, he had a very clear idea about the role so I don't think my advising on strategy and policy was common. There was, of course, dialogue in the Trustee Board and with the registrants, but I didn't see that as a prime part of my role, no.

Q. The chair and deputy chair, the Reverend Alan Tanner and Mr Grinsted, was the deputy chair, was he, at the start?

A. That's right, yes.

Q. You said there was no question of you providing that kind of advisory role; why was that?

A. I think I had was because they didn't feel they needed it. They were both very clear in what they understood to be the aims and objectives of the trust and regarded me and the staff team as there to implement those objectives.

Q. You've described in your statement when you arrived at the Macfarlane and Eileen Trust you knew very little about haemophilia, HIV or contaminated blood, so it was a steep learning curve. How did you go about educating yourself in those matters?

A. In those days there wasn't much of an Internet so one couldn't Google anything, so you had to find papers, and obviously having done an MBA I was familiar with

research, and I read and I talked to people. Some of the staff team had been there a while, and they understood far more than I and were very able to fill me in and, in particular, meeting and talking with registrants, and that was a steep learning curve.

Q. You described in your witness statement as well that the board of trustees when you first arrived were -- and this is the way you put it -- mainly ex-military post-World War II veterans, financial men who were very guarded with the fund; is that right? Was that your impression of the board of trustees?

A. That's my recollection, yes.

Q. How would you describe their understanding of and relationship with the beneficiary population, and the challenges that they faced?

A. Well, the Trustee Board, as I think I've stated a number of times, was made up of people with haemophilia, or members of the Haemophilia Society, who had a great in-depth knowledge of haemophilia, people -- there was nobody on the board with HIV. Alan Tanner had, of course, lost his son to HIV and haemophilia. I am never sure quite what Clifford Grinsted's relationship with the haemophilia and HIV aspect, I think he was brought in -- to the best of my knowledge, he was invited in by Alan Tanner who knew that he had a great in-depth

knowledge of managing money.

The other trustees were either, in the case of one of the appointments by the Department of Health, Mark Winter, who was a centre director and knew all about haemophilia, and the other appointment from the DoH side related to that was a haemophilia nurse from one of the Haemophilia Centres, I forget which one. There would have been two other Department of Health -- and I can't remember their names at the moment. The other trustees would all have been members of the Haemophilia Society and would have been very familiar with both haemophilia, from either their own experience or their children's experience, and with HIV.

Q. You've also said in your statement that your recollection was that the trustees would rather money was gaining interest in the bank account rather than providing that money to families in need. Why do you think that was?

A. I think that certainly the Trustee Board felt it was their responsibility to look after and grow the amount of money that had been transferred to set up the trust in 1988 and I think they felt that, at that stage, there were regular payments being paid, albeit very modest, to the registrants, and there was a schedule of the kind of grants, with guidance as to how much was paid for each

grant area, and that they should stick strictly to those guidelines, not move beyond them, and not be over generous. That was the case that I got.

Q. Was your approach different?

A. Yes, I think it was.

Q. Did you have any allies in the board, was there anyone sympathetic to your approach on the board in the early years?

A. Certainly Chris Hodgson, who was the chairman of The Haemophilia Society as well at the time, he was very sympathetic. He obviously knew a lot of people through the Society and through his own personal contacts, through schools, and he was very well aware of the extent of need. He knew many families, particularly who had been, if you like, youngsters, with him when he was a young boy with haemophilia.

He's the one who stands out. I'm sure there were others.

Q. Did the difference in approach that you've described make for a difficult relationship with the board?

A. No, not difficult. I think they were surprised that my approach was that we should look more closely at the needs of the registrants and perhaps move away from or not be so rigid with the guidelines that were produced for grant making.

Q. We'll come on and look at the guidelines, and so on, in a little bit more detail later on this morning.

You describe in your statement that you were given information by Wing Commander Williams and the Reverend Tanner, when you first started at the Macfarlane and Eileen Trust, about how the Macfarlane Trust had been set up. Can you recall what was said to you about that?

A. Well, I was told it had been set up by Government in order to recognise the impact that had been had on the lives of the children and mostly young people who had been treated with the cryoprecipitate, the Factor VIII, and that this had been introduced to ease the risk of great bleeds, which (inaudible) disability, and that the fund was to be used to make up for the deficit in their lives caused by the treatment and the infection with HIV.

Q. Were you told anything at that stage about the HIV litigation and the settlement agreement and, indeed, the waiver that the registrants had signed in order to receive money from the Department of Health?

A. I almost certainly was told it. I don't think it had much of an impact at that early stage.

I think all I was aware of at that stage was there was money in a fund to be administered by the Trust for

the benefit of all the registrants.

Q. Were you aware from the beginning, from when you first started, that most, if not all, of the registrants were co-infected with hepatitis C?

A. No.

Q. Can you recall when you did become aware of that?

A. I joined in '97. I would have said by '99, certainly 1998/99, it was becoming more of a feature, recognised in The Haemophilia Society and in the Macfarlane Trust.

When I first was told about hepatitis C, it was explained to me that it had not been regarded as a significant issue at the time, because HIV was so much more serious and was likely to probably mean that most of the registrants would die before hepatitis C became an issue. And, of course, it wasn't known as hepatitis C then; it was known as non-A, non-B virus.

Q. Were you -- you also make mention in your witness statement about there being a cut-off date for the Macfarlane Trust of 2012. What were you told about that and by whom?

A. I cannot clearly recall when that became an issue. Certainly, I was not told that at the beginning when I joined. I think I expected that it would go on for the natural life of the registrants. I think it became clear to me over time, but I can't say exactly when, but

it would probably have been 1998 or possibly early '99. Certainly, by the time that we started to carry out the strategic review, there was a growing awareness of it.

Q. And was that something that was discussed much during your tenure, either at board level or with the Department of Health? Was it something that was quite shelved?

A. Do you mean --

Q. The 2012 --

A. You mean the increasing --

Q. The 2012 cut-off date.

A. When -- after the strategic review, that's the first of our reviews, I think by then we did realise that there was a likely termination date, and I understood that to be 2012. And at that stage, it became clear that after 1997, when the introduction of combination therapies had occurred, that the life expectancy of the registrants was very uncertain but likely to be longer and not -- and that it was no longer a terminal illness.

We were aware that there would be a continuing need for support from the fund for a good long time to come.

Q. So is it right to understand the information about the 2012 cut-off date was information that was -- that came from within the Macfarlane Trust itself, rather than from the Department of Health, for example?

A. I never recall the Department of Health mentioning that date.
Q. So it was an understanding that you picked up. You picked up discussions with those within the Macfarlane Trust that there was an end date, but by the time of the strategic review, when it became clear that that would be inappropriate, is it right to understand that that was quietly shelved?
A. I don't think it was ever shelved at all. I think there was a growing awareness that the Trust would need to continue, and at that stage I think we started to advise the Department of Health that the needs were changing for the registrants and that the support from the Macfarlane Trust was likely to go on for longer than had first been envisaged.
Q. You've mentioned the advent of new treatments, triple therapy, and increased life expectancy for those suffering from -- infected with HIV.
Was there a feeling when you started at the Macfarlane and Eileen Trust that this was a significant change that the Trust needed to be aware of and take into account?
A. Definitely. Yes.
Q. I'm just going to take you to a document to get an idea of the numbers of registrants. Can we go to, Soumik,

MACF0000005_041. This is one document -- the Inquiry has received this document in this form. It's not these minutes I want to take you to, but just to talk you through the documents.
So there's trustee minutes from 10 February 1998, and then if we go through to page 7 of the document, which is the first document that comes after the trustee minutes, there's an administrator's report which goes over to page 8. And then the document I want to take you to is page 9, and you will see there that it's a document entitled "Statistics summary at 30 April 1998". I'm unclear why that's part of the same document from the February '98 minutes -- meeting minutes, but there we go.
Just before we look at the detail on this document, were these documents generated by you or by your staff for board meetings?
A. These would have been prepared by the staff team. By April 1998, I believe we had a finance officer in post -- in fact, I'm virtually certain we did -- and it would have been his responsibility to prepare these in discussion with the staff.
Q. And they would have been provided to trustees for board meetings, would they?
A. Probably not every board meeting. Certainly regularly

they would have been provided.
Q. So looking, then, at the top half of the page, we can see that we've got numbers of registrants, both living and deceased.
A. Yes.
Q. So it looks like by 30 April, there were 480 living registrants. Are we to understand that that 480 number are those people with haemophilia infected with HIV by contaminated blood? That's --
A. That is certainly my understanding of that figure, yes.
Q. And 759 had already died, which meant that there were, within that cohort, 1,239 registrants registered with the Macfarlane Trust?
A. Yes.
Q. And then looking down below at E, we've got partners with HIV, 31. So those are -- sometimes we see in documents those -- that cohort of registrants identified as infected intimates --
A. Yes.
Q. -- and 22 were --
SIR BRIAN LANGSTAFF: Well, I think you have to include the widows with HIV for that as well, wouldn't you?
MS SCOTT: Yes.
A. Partners and widows.
MS SCOTT: Yes, partners and widows. 31 partners, 21 widows

still alive, infected intimates. And then 338 widows alive; 19 had already died, and -- well, in fact, 338 plus 135 widows still alive --
A. Widows with dependant children.
Q. Widows with dependant children. 24 widows had died, 5 of whom had dependant children. So --
SIR BRIAN LANGSTAFF: Can you just help with this: widows either have or haven't dependant children. Where the class is set out at F, of "widows", is that widows without dependant children, or is it all widows?
A. I'm afraid I can't answer from this distance of time.
SIR BRIAN LANGSTAFF: Thank you.
MS SCOTT: And, equally, the same might be said of H. Does "widows" encompass widows with dependant children and widows with HIV? Do you know the answer to that?
A. No, I don't think it does, no. So widows with HIV, um, some of them probably also had children. In fact, I know they did.
I'm sorry, but this is a record that I inherited from the original days of the Trust, and I don't think I ever actually questioned that presentation.
Q. So the number at F, "widows", may be a total number of widows but it may not?
A. Gosh, I'm sorry. I'm afraid at this distance of time I cannot answer that.

Q. I'm going to ask you some questions now about the staff team, and I'll do that by reference to a document. That's, Soumik, MACF0000176_009. This is the MFT handbook. Can you just tell us what the MFT handbook was and who saw it?

A. The handbook was for the registrants and for our guidance in the office, and obviously the trustees were -- they encouraged the distribution of it. Again, this is something that I inherited. It was something that had been done since the foundation of the Trust.

Q. Was it something that was printed every year, or a new one done every year?

A. I can't recall at this distance. It was certainly something that was always made available to the registrants.

Q. Certainly we've got, during your tenure, one from '98, '99, 2000. I don't think we've got 2001 and 2002. Could that because there wasn't one in 2001 and 2002?

A. I wish I could answer that question, but I can't.

Q. Soumik, can we go to page 19 of that document? We'll look at various different parts of this document, but I just want to start at page 19. So that's where it sets out who the trustees were, and over the page at page 20, it sets out the staff team.

So we can see a picture of you and 1997, which

indicates you started in 1997. And we can see there that Claudette Allen was the social worker, and she -- is it right to understand she would have started in 2000?

A. That's right, yes.

Q. And she replaced, did she, Fran Dix --

A. Yes, she did.

Q. -- who was the previous social worker who started around about the same time as you in September, October 1997?

A. Yes, that's right.

Q. And we can see --

A. *(inaudible)*

Q. Sorry?

A. Fran Dix started in October '97. There was a previous social worker whose name escapes me at this moment.

Q. Mr Tudor Williams?

A. Yes, that's right.

Q. We see Claudette sets out what her role was at the Trust:

"Claudette is our social worker and is responsible for all types of help and advice to registrants. She can answer queries about Trust payments and provide advice and help about most aspects of living with HIV. [She] is in regular contact with Haemophilia Centres and The Society, and she can contact local authorities and

other bodies on your behalf."

We can also see there Carol. I understand that's Carol Clisby; is that correct?

A. Yes, that's correct.

Q. And she was your -- the Macfarlane Trust's benefits adviser who began in 2001?

A. Yes, I think, yes.

Q. And did she take over from Jenny Jackson who was the previous benefits adviser?

A. Yes, she did. There may have been a slight gap.

Q. And we see there that:

"She deals with queries about Social Security benefits, can sort out problems with the DWP, and help with appeals against unsatisfactory decisions, and attend appeal hearings if necessary."

She also -- if we turn over the page to page 22, there's some pages entitled "Welfare benefits". Would Carol Clisby have been responsible for drafting these -- this sort of information for the handbook and indeed for newsletters and so on?

A. Yes, she would, and Jenny before her.

Q. If we go back to page 20, we can see the rest of the staff team. We've got Rodney Shepherd, I believe, who is finance officer?

A. Yes.

Q. Roz Riley, administrative secretary --

A. Yes.

Q. -- and Lisa -- I'm afraid I don't know Lisa's second name -- finance assistant. So that was the staff team in 2003.

A. Yes, it was.

Q. And the size of the team, it was broadly consistent, was it, during your tenure?

A. When I first arrived, there was Jenny Jackson as benefits advisor. There was Peter Williams, a social worker. There was Funmi Hassan, who did all the administrative work, and there was John Williams.

Pretty soon after I joined, I felt we needed more robust financial support in the office, and the deputy chairman agreed, and so the finance officer post was created.

Q. And in addition to these staff, so employees, is it right that Susan Daniels was also providing independent financial advice to registrants, or financial advice to registrants?

A. Yes. I'm not quite sure when that arose. Susan -- Susan was available to registrants about the time that I joined, and maybe for longer. I'm not sure when her help was introduced, but it was certainly -- at that first stage, she ran her own private business, providing

advice. Later, she joined a company, providing advice on financial matters and investment.

Q. And Susan Daniels is due to give evidence to the Inquiry, so we can no doubt ask her those questions.

A. No doubt.

Q. Soumik can we go to page 7, please, of this document -- page 8 of this document. So here we've got the section "Financial help from the Trust", and this is the section that sets out the different payments that can be obtained from the Trust. So if we go over onto the following page, we can see here the regular payments, winter payments, and then if we go over the page, single payments. So were those the three types of payments made by the trust during your time there?

A. Yes, they were. The additions, obviously, were related to housing and debt, which would have depended on Susan's recommendations to us, and quite a lot to do with loans and equity loans, et cetera, but I'm sure we'll come on to that later.

Q. We'll come on to that, but the payments or the grants or the payments that would have been made to registrants to discharge debt, or in relation to housing, leaving to one side the equity share loans, would either have been single payments, would they, or potentially loans?

A. Yes, yes.

Q. There wasn't a category of grant in its own right?

A. It wouldn't have fallen within the grant, the normal grant guidelines.

Q. I understand.

A. These were discretionary payments and, depending on their size and their need, it could have been a direct grant. More often, it related to housing debt. It probably would have been some kind of loan, either secured by charge on the house or an equity loan agreement, which I think is something that had been started fairly early on in the life of the Trust.

Q. We'll certainly come back both to the issues you raised there, the discretionary payments outside the guidelines and the loans.

A. Yes.

Q. So if I can start, then, on looking at regular payments. Soumik, can we go back to the page before? So we look at regular payments, and it sets out there the substantial increase in regular payment from September 2000, and I'll ask you some questions about that in due course, and then saying that there's a further review that is going to be taken, unlikely to lead to major revisions:

"Who can have a regular payment?

"Everyone registered is eligible for a monthly

payment at some rate, just ask."

Is it right to understand that, talking there about those that are registered, meaning what we sometimes see referred to as "primary beneficiaries" --

A. Yes.

Q. -- ie those people with haemophilia infected with HIV?

A. Yes. Regular payment also paid to widows, and for -- to infected intimates at different rates.

Q. Yes, we'll come on and look at that.

A. Yes.

Q. It says there "just ask". So is it also right to understand that, in order to get a regular payment, you needed to make an application for one?

A. No, because at the outset of the Trust, regular payments word part of the package of benefits to the registrants and we had a complete list of registrants.

Later, there would have been circumstances which changed, for example, when infected intimates -- when we became aware of infected intimates or indeed of children born with HIV, so there would have been increases. Those would have been advised to us mainly by the Haemophilia Centres. They would have advised that there was someone else who should rightly expect to receive a regular payment.

Q. So was it the case during your time there that everybody

who was registered with the Macfarlane Trust received a regular payment?

A. Yes, I can't think of anybody who didn't and any reason why they shouldn't have.

SIR BRIAN LANGSTAFF: May I just ask, suppose the case of somebody who has HIV, who is a primary beneficiary, to use those terms, they have a family, they die. Because they had HIV and because of the care given to them by members of their family, the family suffers from greater hardship than they would have had if he had not had HIV, but he is no longer a registrant because he's dead.

A. Yes.

SIR BRIAN LANGSTAFF: Potentially, you have a number of further registrants, do you, because they are within the terms of the original trust deed; they are dependents and widows, or spouses or partners.

A. There would have been payment to widow.

SIR BRIAN LANGSTAFF: But not to the children? What if the person who dies is a single parent?

A. Sorry, you'll have to expand on that. You mean if there was -- most of the people who died at that stage were men, fathers.

SIR BRIAN LANGSTAFF: Yes, but they may have been responsible for children, their wife may have died -- assuming they'd been married, their wife may have died

or they were no longer living together in circumstances in which he would have the care of the children. That would leave the children. Would they, if they had been dependants, they would be within the terms of the Trust? Would they be regarded as registrants or not?

A. Yes, they would continue to be dependants. In some cases the dependants, if they had neither parent available, would have been looked after by grandparents.

SIR BRIAN LANGSTAFF: Yes.

A. As I think we'll look at later, there was a case in the Eileen Trust where there was nobody available, except for a lady who took on the foster mothership of children after (inaudible) shortly before she died.

SIR BRIAN LANGSTAFF: But so far as the children were concerned, they would be within the terms of the trust deed, would they receive any regular payment or not?

A. I think the payment would have -- if they were infected, and some of them were, then they would have their own payment, yes. If they were not infected but dependent on the father, as his dependant, then they would continue to be supported by the Trust until they were 18, and if they went on to further education, they would be supported through that period of further education.

SIR BRIAN LANGSTAFF: Now, did that support come in the form, in part at any rate, of regular payment or not?

A. It did, yes.

SIR BRIAN LANGSTAFF: Thank you.

MS SCOTT: Can we, Soumik go to page 11, now. These regular payments were paid monthly; is that right?

A. Yes.

Q. The regular monthly rates are set out on this stage.

A. I'm going to reach for my specs. Oh, that's better. I can read that. Yes.

Q. At A we've got the standard rate available to all registrants is £255 and then depending on the make-up of the household, that might be increased for a partner or for a dependant child.

A. Yes.

Q. Then we've got the higher rate available to those who claim certain -- who are in receipt of certain benefits and that's £305. Again, that's uplifted to take account of the make-up of the household. Is it right to understand that this system was designed to give higher monthly payments to those with the least income, and that --

A. Yes.

Q. -- that was assessed by using the benefits as a proxy for working out who had the lowest income?

A. Yes, I'm not sure about the use of the word "proxy" because our benefits adviser would have been very aware

of the benefits status of anyone in need of being paid benefits and she would have obviously advised the trustees of this situation. So it wouldn't have been ad hoc, as it were. It was just that if they were on one of those above qualifying benefits, there would have been an addition to what they received from the Trust in regular payments.

Q. Yes, so the point I wanted to establish with you is that there wasn't an additional assessment of the income and expenditure of the individual -- of the registrant -- by the Macfarlane Trust. You --

A. Certainly not during my tenure.

Q. And for the regular payment. It was you got the higher rate if you were in receipt of certain benefits?

A. Yes.

Q. So that's what I meant by proxy.

A. Yes, I see. Yes, okay.

Q. Then coming down to "Partner who is HIV positive". It looks here as though the partner who is HIV positive gets the £255 standard rate, if in receipt of certain benefits, then another £61; is that right?

A. Let me just catch up with that. Yes. Yes, I think so.

Q. So that puts them on the same rate as -- that is effectively rate B, higher rate?

A. Exactly.

Q. Is it right that that was a change that took place during your tenure, that previously infected partners had received a lower rate than the person with haemophilia who had been infected with HIV?

A. Yes, it was slightly lower. I think, as a result, I'm not sure of the date of this particular piece of paper I'm looking at, but certainly at the time of the strategic review and the time of the review of regular payments, I think these things would have come to light and there would have been discussion at Trustee Board level. I cannot recall, I'm afraid, what changes took place and when.

Q. Sorry, Ms Hithersay. I think I've asked a question on the wrong premise, so can I just go back a question. I think I suggested to you that a partner who is HIV positive was receiving, under this scheme, the same rate as the person with haemophilia who is infected. In fact, I don't think that's correct. So the person with haemophilia --

Is it right to read the scheme in this way: a person with haemophilia who is in receipt of income support, for example, will get the higher rate of £305? If they also are in receipt of the higher or middle rate care component of the Disability Living Allowance, they will get an additional £61, is that what we understand

from --
A. Yes, that is, yes. That is what we understand.
Q. For that person's partner, who is infected with HIV, so we're looking here at "For partner who is HIV positive" --
A. Yes, yes.
Q. -- even if they receive, for example, income support, they will only receive the standard rate of £255, although if they are also in receipt of the higher or middle rate care component of Disability Living Allowance they may also get the supplement of £61.
A. Yes, from my knowledge at this point in time, I would say, yes, that seems logical but I cannot state that as a certainty.
Q. So why was it, assuming that what I've just put to you is correct, which I think you've accepted it probably is, why was it that an infected partner received less by way of regular payment than the person with haemophilia who was infected?
A. I can only say that I don't know for certain but I would think it likely that because of the situation of somebody with haemophilia who developed HIV meant that they already had the pre-existing condition of haemophilia and, in many cases, would have had disabilities relating to that.

Q. So you don't know for certain but what you're describing is effectively a policy decision on the part of the Macfarlane Trust that the person with haemophilia should get more than the infected partner?
A. I think it is possible to look at it that way. I think when the Trust was first set up it was very clearly seen that the group that would become registrants were all people with haemophilia and, at that stage, it was not anticipated, or probably not really recognised that, in fact, many of the partners and widows, wives, of those who had become infected would also become co-infected. I don't think that when the regular payments were first set up, it would be anticipated that regular payments would later be paid to partners and children who subsequently became infected.
Q. But we know, for example, that there was a review of the regular payments in 1999 because we just looked at that part of the handbook, and this discrepancy in the rate survived that review, so I suggest to you there are two explanations why that could be. One is it's a policy decision on the part of the trustees that the person with haemophilia who is infected should get more, is deserving of more by way of regular payment than the infected partner who does not have haemophilia. So that could be the first explanation.

The second is, and possibly related to it, there simply wasn't enough money to give both the same rate and so a hard decision will have to be made and it was to give the partner a lower rate. Are you able to assist --

I'm not sure that's a choice, actually, because the second is also a policy decision, isn't it?

MS SCOTT: Yes.
SIR BRIAN LANGSTAFF: So your first question, is it a policy decision or is it something else, actually, you've answered it.
MS SCOTT: Yes.
A. Certainly, during my tenure, there was never a policy decision to pay less money to infected intimates or children. It is my understanding that the situation developed over time and that the trustees -- before I joined, certainly -- that the trustees would have come to a decision that regular payments should be paid to anyone who was infected with HIV through blood products or through intimate relations with someone who was infected.

At some point in time before I joined, there must have been a decision about how much should be paid. Now, I have no knowledge of how that decision was to come about, or whether it was a policy decision as such.

I don't think, in my tenure, that there would have been a question of one person being more deserving than another. I think they would have referred back to the trust deed which was about people with haemophilia who had been treated with infected blood.

I also don't think that there would have been any question of such a decision being influenced by perceived lack of money. Obviously, it would have been a situation which had to be considered early in the life of the Trust, and I have no knowledge of how that decision was reached. But I don't think we should assume that it was dependent on a view that one person was more important than the other.

Q. If that was a policy decision, would that be wrong, in your view?
SIR BRIAN LANGSTAFF: I think that's really a question ultimately for me, isn't it? One can see that the scheme was not a scheme to compensate those who had got HIV. They had to have it through infected blood products, and that was the original scheme.
A. Yes.
SIR BRIAN LANGSTAFF: So it's those who were suffering from HIV as a result of having infected blood products, or the needy spouses, parents, children, other dependents of such persons. So it was envisaged, as I read the

trust deed from the start, that those who were needy spouses, parents, children and other dependents were within the class who would benefit from the discretion of the trustees.

I can understand that there may have been an argument one way or the other about whether those with haemophilia actually had greater needs which needed to be satisfied on a regular basis because of the devastating effects of that condition, quite apart from HIV. But that's a decision ultimately for me to weigh, I think.

MS SCOTT: Can I put it a slightly different way. Do you have any recollection of there being different rates under the regular payment scheme during your tenure for those people with haemophilia who were infected with HIV and their partners infected with HIV? Do you recollect that as being an issue?

A. I don't recollect that as being an issue, no. Once somebody was infected with HIV, either through direct blood-related treatment or through intimate relations with that person, then once they were infected with HIV, they would have become a registrant of the Trust, and they would have been eligible for regular payments.

Without looking at the schedule, going back, I cannot tell you whether the rates were exactly the

same or not.

Q. So you would have expected, would you, that partners infected with HIV and people with haemophilia infected with HIV should be treated the same?

A. They would all receive the standard rate unless there were additional reasons for supplements.

Q. So to be --

A. That's my recollection.

Q. So to the extent that this policy that we looked at doesn't reflect that, can you help us as to how that policy could have come about?

A. As I think I tried to explain, I think the policy is one of those many things that in the Macfarlane Trust grew like topsy, you know. It had started off with one understanding of the situation, and that situation had changed over time, and the Trustee Board at the time would have responded to how they perceived the need and how it should be responded to at the time.

Q. Can we look then at the position for widows and dependents. So we see here for six months following bereavement, widows receive whatever rate had been paid to their partners, except for the supplement payment, and the supplement payment is the £61 that the person with haemophilia would have received --

A. Yes.

Q. -- if they had certain --

A. That was related to mobility, yes.

Q. And a transition payment is also available for those caring for orphans.

So just pausing there, are we to understand that all widows were paid the same as their partners for six months, except for the supplement payment --

A. Yes.

Q. -- no matter what the circumstances were?

A. That's my recollection.

Q. It's your recollection?

A. They were also paid a bereavement grant.

Q. And then there's reference there to a transition payment available for those caring for orphans. You were giving some evidence in relation to that earlier. Does that prompt your memory in any way? Do you recollect what a transition payment was?

A. No, I don't.

Q. It gives the impression that it's a payment that's not going to last for very long.

A. No, it did not -- it did not last very long.

Q. Then after six months, six months after the bereavement, widows whose circumstances are not described below will get paid a further £100 per month for a further nine months?

A. Yes.

Q. And so those widows not described below, is it right to understand that their support and funding would be cut off by the Macfarlane Trust one year and three months after the bereavement, no matter what their circumstances were?

A. That is my understanding of what was available at the time. However, I do know that what would not have been cut off from them would have been advice and support from the Trust in other ways, particularly the benefits adviser and the social worker who would have helped them obtain extra income and support through statutory services.

Q. Were -- did that -- so let's just look, then, at working out who this class of widows are.

So widows who are themselves HIV positive will be paid without time limit at the appropriate rate for a registered person. So it seems from this that once the person with haemophilia has died, the widow is no longer classed as a partner who is HIV positive but actually becomes the registrant themselves and can claim the standard rate A or higher rate B; is that right?

A. That is correct.

Q. So it doesn't include widows who are HIV positive. It seems to -- and it doesn't include, it would seem,

incapacitated widows or widows with children; is that right? Their support continues?
A. Yes, that's right.
Q. So that class of widow who gets cut off from financial support after 15 months are non-incapacitated widows without children?
A. Yes.
Q. Did you consider that that was appropriate as a policy for Macfarlane? Did you have any concerns about that category of widow being unable to claim, unable to receive money after 15 months?
A. I didn't question that. That was a situation that had been there when I joined, and it wasn't a decision that I questioned. However, what I did question was continuing level of other support to them and the importance of that, and I think that will become obvious later on in our discussion.
Q. So were you not aware of great hardship from that cohort of widows who suffered as a result of this policy?
A. If and when we became aware of great suffering, we would try to help them in the way that I think I've just described: either through our benefits adviser helping them obtain more income in terms of grants from the state or increased payments from the state, or in providing them with support services. Later on,

obviously, bereavement; meetings and other meetings which, of course, they were welcome to join.
But, no, I did never question the trustee decision which had been taken long before I joined, but after a period of time, the widows without children would cease to continue to have support from the Trust.
Q. The Inquiry heard yesterday from -- well, over the last two days from Peter Stevens who was asked about support for dependents and widows, and the view that he gave was that it was inadequate. Would you agree with that? Did you think that the support that was given by Macfarlane was inadequate?
A. Well, with hindsight, yes.
Q. But at the time, that didn't occur to you?
A. At the time, I didn't see any possibility of the funding situation being looked at. So, therefore, the only -- the only avenue I could see at that time to assist them was to ensure that other areas of help were -- remained -- from the Trust remained open.
Q. And you didn't see any possibility of the funding position being looked at by -- was that by the Macfarlane trustees themselves, or are you talking there about the Department of Health providing more money to the Macfarlane Trust, or both?
A. At the time, there were many things about the way the

Trust had been set up that I simply accepted. It was only over time that it became clearer that needs were changing and some needs were not being adequately met. Because there were very many needs in very many different areas, this is not one that I particularly looked at from recommending an increased, either in terms of time, support, or amount, for widows who had died who didn't have dependant children and were quite fit in themselves.
Q. So is it right to put it like this: at the time you didn't question this policy, but now, looking at it with hindsight, you can see that the provision for widows and dependents was not adequate?
A. Well, you're asking now about two different areas, aren't you. You're talking about widows -- I'm speaking about widows without children who were fit, and you're bringing in with the dependant children.
Now, as far as I'm concerned, payments for widowed mothers with dependant children would have depended upon the rates that we can see here, unless they were infected, or unless their children were infected, in which case they would have been increased.
Again, I think I was probably guided by past precedent, and it would be very easy to agree with Peter in saying that of course we didn't do enough. I mean,

right through, the way -- the way that we operated, perhaps lacks the generosity -- lacked the generosity that we would now feel should be available. Hindsight is wonderful.
Q. So looking at it with hindsight, which is what you're being asked to do, can I just understand your evidence. In relation to widows without children, so that cohort that were -- after 15 months had no funding --
A. Yes.
Q. -- are you saying that you agree with Mr Stevens that that support was inadequate?
A. I would agree with Peter that it was -- that the financial support, with hindsight, was inadequate.
Q. The financial support?
A. I do know that we did try and encourage and help people to become better qualified, and that was nothing to do with a cut-off date related to their payment support from the Trust --
Q. And then --
A. -- continued to offer --
Q. Sorry. Do finish.
A. We continued to offer help in other ways. But --
Q. Then in -- sorry.
A. As long as it was needed. As long as they kept coming back for it.

Q. Then, in relation to widows with dependants or incapacitated widows, so those are the cohorts of widows who continued to receive financial assistance from the Trust --
A. Yes.
Q. -- we can see there that the rates are £100, if incapacitated, per month, £100 for the first dependant children and £30 thereafter for any further dependant children. So would you agree that the rates that are being offered to those cohorts of widows are lower by quite a substantial margin than the rates that the family would have received from the Macfarlane Trust during the lifetime of the primary beneficiary?
A. Yes.
Q. Now, looking at it with hindsight, does that cause you any concern and does that cause you to consider whether or not those payments were adequate?
A. Well, yes, of course it does.
Q. Does it follow from that, then, that there were areas of unmet need within the widow and dependant community during the time that you were at Macfarlane?
A. Yes, it does.
Q. Is it right to understand, or would you agree with the evidence that the Inquiry heard from Mr Stevens, that the reason for that was because the Trust was

inadequately funded by the Department of Health?
A. That is a very difficult area because I found during my tenure that each time we went to the Trust with recommendations for higher payments, due to changing needs, that was not refused. So it would not be right to say that that was purely due to inadequate funding from the Department of Health. It would be also accurate to say that we did not highlight that particular area of need to them and ask for substantially more money to support the widows without dependants and -- well, indeed the -- all the widows, except those who were infected with HIV. They all could have had greater support and didn't, and that was partly our lack of bringing that to the notice of the Department of Health.
MS SCOTT: Sir, I note the time. I have a few more questions on the regular payments and questions on the other payments, but I can pick that up after the break.
SIR BRIAN LANGSTAFF: Well, if it's convenient now, then we'll take a break.

This is a break of about half an hour so we'll come back at quarter to 12, Ms Hithersay. During that period, you'll have heard me say, I think on earlier occasions if you've been watching, that you're giving evidence. The rule is that you must not discuss the

evidence you have given or any of the evidence which you think you might yet have to give or be asked to give, with anyone, whoever they are. You can talk about anything else you like.

Look forward to seeing you back here at quarter to 12. Thank you very much.

(11.15 am)

(A short break)

(11.45am)

SIR BRIAN LANGSTAFF: Yes, Ms Scott?
MS SCOTT: Ms Hithersay, can you see and hear me?
A. I can, yes. Can you see and hear me?
Q. I can. Can I just ask you to clarify one of the answers you were giving just before the break. The sound wasn't terribly good, and I just want to check the answer.

I had asked you whether you agreed with the evidence from Mr Stevens that the Macfarlane Trust was inadequately funded by the Department of Health. I am just going to read you the transcript of what you said, and just check with you to see if what you said was what you meant, or --

So I said, "Did you agree with Mr Stevens that the Trust was inadequately funded by the Department of Health?"

That was the question.

Your answer was:

"That is a very difficult area, because I found during my tenure that each time we went to the Trust with recommendations for higher payments, due to changing needs, this was not refused."

Did you mean --
SIR BRIAN LANGSTAFF: It was the Department, not the Trust.
A. Yes, yes. I meant the Department of Health.
MS SCOTT: You meant the Department of Health, thank you.

We were, before the break, looking at the regular payments scheme set out in the Macfarlane Trust handbook. Soumik, can we just have that document back up, please. It's MACF0000176_009, and it's page 11 of that.

I'm going to ask you some questions about -- we have spoken about -- I'd asked you questions about widows. I'm just going to ask you some questions about orphans. The only point at which this scheme refers to orphans is just below "Widows and Dependants" where it says:

"A transition payment is also available for those caring for orphans."

I think you accepted that that was not a long-term regular payment.

Do you recall -- am I right in understanding -- that this scheme doesn't provide for regular payments to

orphans as set out here?
A. Certainly, if the orphans were dependants of the primary beneficiary, they would continue to be supported as dependants of the Trust until they reached the age of 18.
Q. Would you accept that that's not set out here as part of this scheme here. That is not clear on --
A. It's not clear. It says a transition payment is also available for those caring for orphans. Yes, it doesn't spell it out. It should spell it out more clearly.
Q. So that seems to be the extent of the payment for orphans set out here. I think we can agree that; is that right?
A. It says:
"Guardians [or] carers of orphans will be paid the same rate as widowed mothers."
That would continue for as long as those children were dependants.
Q. Where does it say that?
SIR BRIAN LANGSTAFF: Footnote 2.
MS SCOTT: Sorry, footnote 2.
So here, under this policy, guardians or orphans are paid same rate as widowed mothers?
A. Yes.
Q. So the ongoing payments for orphans will be equivalent

to £100 for the first dependant child and £30 for any subsequent child?
A. That's what it suggests here and I'm afraid I cannot recall at this distance of time if that is how the payments were calculated at the time.
Q. In relation to families in these circumstances, I wonder if you can help us what the situation is here.
If there are parents who are -- parents, a family -- father, person with haemophilia infected with HIV, mother, and children, and then there is a divorce, is it right to understand that if the father dies, the mother would not be treated as a widow under this policy?
A. I know that the children continue to be treated as dependants of the Trust until they were 18. Now, if there had been a divorce, and so during the period before the registrant's death there had been no financial dependants, then certainly that person would not have been recognised as a widow after the registrant's death. That is my recollection.
Q. So, under this scheme, at least, there would be no scheme of regular payments for children in circumstances where their parents had divorced before the death of their father?
A. No, that is not what I suggested. The situation was that those children, whether or not the father was

alive, if he had been a registrant of the Trust, those children would have been dependants of the Trust until they were 18, or until they completed their further education. Those payments, when they were minors, would have been paid to the mother.
Q. My question was unclear, so it's my fault entirely. I understand that's what you were suggesting. My question is: that isn't what's set out in this policy; can we agree that?
A. It's not set out like that. I should stress that this is not a policy; it's a guideline of what the payments were. I think it would be looking at it too rigorously to call it a policy. It was guidance and if people were not clear what their situation was, then they would come and get in touch and we would try and clear it up, resolve it.
Q. Can you recall whether there was a policy that set out the payments that the Trust would make to children in such circumstances?
A. "Policy" is such a tricky word. There was certainly guidance and there was certainly an assumption that from the inception of the Trust that any children born to a registrant would be dependants of the Trust until they reached majority, whether or not the father died.
Q. The Inquiry hasn't to date found a policy setting that

out in terms. The only guidance that the Inquiry has found to date is to say that it's at the discretion of the Trust. Does that sound --
A. Yes, I think that would stand. There was guidance, and there was always discretion, and each case was viewed on its merit, and obviously these -- all these rates are here for guidance, and there would have to be special reasons why they were not adhered to, and you just pointed out an area where it's certainly unclear. But that doesn't mean that there wouldn't have been an appropriate response at the time. It just means that it's not included in this guidance sheet.
Q. One of the issues that has emerged from some of the evidence that the Inquiry has seen is that there doesn't appear to have been a system of regular payments for such children. Can you assist us with how that could have occurred?
A. Sorry, can you just repeat that? I'm not quite clear.
Q. Yes. So we're talking here about families where there has been a divorce and there are children. The father, person with haemophilia/infected with HIV dies, the mother is not treated as a widow, pursuant to Trust policies as you've explained, and some of the evidence that the Inquiry has seems to suggest that there wasn't a scheme of regular payments for children, those

children in those circumstances, from the Trust?
A. I'm not sure how it was set out in any guidance but certainly during my tenure one or two families came to light where the mother had subsequently moved away with the children and it took us a while to realise that there were dependant children. It was not a deliberate decision to exclude children from being dependants of the Trust because the parents had got divorced.
Q. So, as far as you're concerned, is it right to put it like this: that children in those circumstances should have received regular payments from the Trust until they were either 18 or longer if they were in full time education?
A. That is right, and where children were identified in that category, back payments would have been made and they would have become established dependants of the Trust.
Q. Can you recall any situations where, given that those payments were at the discretion of the trustees, that discretion was exercised against making payments to children in those circumstances?
A. No. No, definitely not.
Q. Can we look briefly, then, at how these rates were set.
Soumik, can we have MACF0000007_137. This is a document "Payments Review Group -- Briefing", dated

December 1999. I think you refer to this in your witness statement and you explain that the Payments Review Group was a group in which Mark Winter and the social workers formed a part; is that right?
A. Yes, that is.
Q. We can see there that it's a briefing on the cost of living with haemophilia HIV and combination therapies, and it says --
A. Yes.
Q. -- at the top there:
"A group of registrants and ... staff met together to reassess the cost of living with haemophilia, HIV virus and combination therapies."
It goes on to say:
"The group considered their way of life, and ways in which the daily cost of living was increased by living with symptoms ... of haemophilia, HIV and hepatitis C related illnesses. [It] compared expenditure in a range of areas, and attempted to determine how this differed and was greater than similar expenditure ... for [an] average family."
Were you part of that group, do you recall? Do you remember doing any work in relation to this aspect of the group's work?
A. Not personally. I do recall drawing together the staff

to see the best way to address this. We probably would have discussed it at a staff meeting. We would have wanted to involve registrants themselves. I cannot, at this stage, recall exactly how the Payments Review Group operated but we certainly would have included discussion with the registrants. We would have included, as is obvious from the membership, those who were working directly with people with haemophilia in the centres. And through the staff team, we would have been talking to both the benefits adviser and the social worker in particular.
We might -- particularly if there were issues related with housing which needed to be drawn into the discussion, we would have involved Susan Daniels.
Q. And it says there, third paragraph down:
"The group used the original 1993 paper produced by the Trust at the time of the last major review of Regular Payments, adding to those where new issues were raised and updating costs related to the areas originally identified."
Then the group goes on to set out the major changes as experienced since 1993. The first one:
"The majority of those living today are unemployed, whereas in 1993, many of those who were well were still in employment. In most cases where men had been in

permanent relationships, partners were also in employment. Today, many relationships have broken down due to the burden of caring and of living with a partner who was HIV positive. Many partners today were unemployed and engaged in caring for their partner and sometimes their children."
Then secondly:
"In 1993, all registrants had received two tranches of capital payment from Government. They were able to afford to by household goods, go on holiday, and afford some luxuries. Today, well over 70 per cent of Trust registrants are largely dependent on state benefits and Trust funding. This meant that the majority of people registered with the Trust are living at or below the poverty line. This is more than twice the national average."
Thirdly:
"In 1993, there was no successful treatment for AIDS. People either got ill and died, or remained asymptomatic and continued their daily life watching many of their friends die and living with a very short life expectancy and no hope. Today, combination therapies means that for many there is a hope of a future, albeit uncertain. Many people will be sick for much of the time, living with chronic illness and

periods of fluctuating health. Sometimes feeling well enough to consider part-time work and sometimes very seriously ill. This uncertainty of life expectancy and quality of life makes planning difficult and adds greatly to the stress level in the family."

So there's a tension here, isn't there, between, on the one hand, treatment having improved and a life expectancy having improved, but as against that, the financial situation, the employment situation, the situation within families in terms of relationships seems to have got significantly worse since 1993.

Is that the background in which the Trust was working during the time that you were there?

A. Yes, definitely. I think it is important to stress that whole area of fluctuating ill health. Because certainly for much of the time when people were not suffering from the effects of the combination therapies, they could enjoy a short period of quite good quality of life. It was the uncertainty, added to the effects of these many therapies, that added to the stress of the family; the situation that the family found themselves in.

Q. As against that background, the group consider the areas and identify the extra costs that would be attributed to living with HIV.

If we could go over the page, Soumik. We can see

there, it's entitled "Detailed breakdown - monthly additional costs", and it goes through a number of different categories. So we go from diet, fuel bills, clothing, skin care and toiletries, cleaning products and washing powder, domestic material, travel, complementary therapies, holidays, communication, and then we go to the bottom of the page. And then that's all totted up to an additional monthly cost of £408.

Then if we go over to the next page, please, Soumik:

"The group worked on costing these additional needs and recognise that regular payments were meant to contribute to, but not necessarily cover, the full cost of meeting the needs. However, they felt the costs identified were a fair and realistic representation of the additional expenditure incurred by the majority of families registered with the Trust today."

Then the next paragraph:

"The Group recognised that if the Trust were to give all registrants and infected intimates a regular monthly payment of £408, it would cost £2.374 million a year at present rates. And payments to widows, independent children and single grants would be an additional charge to the fund."

Then if we go down a few paragraphs below -- two paragraphs below (ii):

"The Group recommended that the basic rate be removed and everyone paid a minimum standard rate which recognised the cost of living with HIV, whether or not they or their partner were able to work some of the time."

And then towards the bottom of that page:

"It would be necessary to advise Lord Hunt that the monthly increase would add to annual expenditure and would mean that the Trust would need to seek 'capital top-up' earlier than had been indicated in the Strategic Review."

Then it refers to schedules which we don't have setting out the effect on cash flow of lower increases.

Can you recall what your view of that piece of work was?

A. My view was that it was very important, that it indicated that our levels of regular payments were quite substantially below what was needed to fulfil the original aim of the Trust deed, also recognising that there were limits in the amount we could expect the Department to increase payments without too much argument.

I mean, the Department tended to support our proposals for an increase in grants, but it was always tricky to gauge how much we could realistically ask for

without questions being asked that would need to go higher within Government. Clearly, Lord Hunt, as the Minister of State at the time, needed to know this, but also he needed to know that our way to address this would be through a capital top-up earlier than we'd suggested before, and that we would be asking for that imminently.

Q. Is this figure, costed as it is by a group of registrants and involving Dr Mark Winter who is not only a Haemophilia Centre director but also an HIV physician -- would that not be precisely the sort of evidence-based funding bid one should be making to the Department of Health in order to meet the objectives of the Trust?

A. Well, the -- we would have sought, after that meeting, a capital top-up. I cannot recall what that capital top-up that we asked for at that time was, but I do know that it would have been certainly influenced by what had been revealed in the Payment Review Group.

Q. We can look next at the trustee meeting at which this piece of work was considered. Soumik, it's MACF0000013_030. It's a minute of a trustee meeting that took place on 1 February 2000, so a month or so after the briefing note.

Soumik, if we go to page 6, we'll see the discussion

that takes place there. It begins at the bottom of the page, and it starts by saying that there had already been an increase of 11 per cent agreed in terms of regular payments.

Is it right that that increase was based effectively on inflation because there hadn't been an increase for some substantial time, and so an 11 per cent uplift was agreed on the regular payments? Does that accord with your recollection?

A. Yes, it does. Yes.

Q. And then:

"The Review Group had recommended that further research be done to identify the additional costs of living with HIV. A small group, including staff, trustees and registrants had worked on this issue, referring to the model used in determining regular payments in '90 and '93. The Group had identified new areas of need that related to long-term survival and the effects of combination therapies. The Group had identified revised costs of living with HIV and had made recommendations to the Payments Review Group based on substantial increases to regular payments and reductions and restrictions to one-off single grants.

"In order to confirm that a move to higher monthly payments and more restricted single grants [over the

page] would be the preferred choice of the majority of surviving registrants, a brief questionnaire has been circulated with the Christmas newsletter. Responses received had demonstrated overwhelming support for such a change of policy."

It then goes on to discuss the forecast of capital requirements presented to the trustee on increasing monthly payments by 75, 100, and 125.

Can you recall why there wasn't even a suggestion made to the trustees that, actually, what they should be doing is increasing the rates up to the £405 that had been identified in the report?

A. So you're asking why I didn't suggest that the full amount should have been acknowledged, following the recommendation of --

Q. Well, I don't know whether it was you or how it came about, but it doesn't appear that the full rate is being even discussed here. Do you know why that is?

A. I don't think it was. Obviously, trustees had been involved in that Payments Review Group. It is my recollection that we trod a careful line between asking for too much and recognising increased need.

Again, with hindsight, it would have been good to have said, therefore, we need the extra 2 million-plus to be added to the amount. Presumably, that was an

annual cost that we're currently expecting from the Department.

I don't believe we did it that way, and I'm not sure whether it would have ever been considered by the Trustee Board. I think they felt they had a responsibility, as I have said previously, to make their demands relate to what they felt the Department could and should accept, rather than asking for too much and creating a lot of debate.

Q. Do you think that is why, perhaps, your impression or your recollection of the Department's response to the Macfarlane Trust was that they got what they asked for because they only asked for what they thought they were going to get?

A. I think you could probably say it like that, yes.

I think we were very careful not to appear too greedy. Now, perhaps in making that decision, we should have erred on the side of registrant need more strongly than possibly we did.

Q. I don't need to take you to the documentation we've got in relation to the meeting with Lord Hunt. Mr Stevens was taken to that during his evidence, but it does show that the £100 per month increase was what was put to Lord Hunt, rather than the full figure identified by the Payments Review Group.

I'm going to ask you now some questions about -- a couple more questions about regular payment, a regular payment, and just really some procedural questions.

Who, on the staff team, was responsible for assessing the level that a registrant got under the regular payment scheme? Was that the social worker?

A. Well, as the previous piece of paper showed, it was a very much dependent on what their situation was. And the situations are shown in different categories. And if, for example, someone was a man with dependant children and a wife, he would have got that rate.

Q. Who on the staff team would be making that decision? Was that the role of the social worker?

A. Well, we would have known the situation about each registrant. We would have either known it directly from them, or we would have known it from the Haemophilia Centre that they attended.

For example, if another child was born, then we would have known about it pretty quickly. But it wasn't up to the social worker or a particular member of the staff; it was just something that we had -- we knew who our registrants were and, by and large, we knew the situation of almost all of them. Usually from personal contact from some member of staff.

Obviously, there were people that later we

discovered we'd lost touch with. That was rare.
Q. Was there any kind of system where the rates were periodically reviewed to check whether or not somebody's circumstances had changed, whether it should be increased or decreased or changed in some way?
A. When we sent out the census form, which we did periodically, that would enable us to check through all the details that we had and make sure that they were correct and up to date, and occasionally we would find there were errors.
Q. Was the census form sent out on an annual basis?
A. No, no. We certainly sent out like a census form for the two reviews. I'm quite sure one had been sent out before I joined. It was a bit like our United Kingdom census. It was done when a need was recognised to update our situation and our knowledge of the group.
Q. That form would ask for information about the family situation of the registrant --
A. Yes.
Q. -- the financial income and expenditure of the household; is that right?
A. I'm not sure that we always asked for that with the census form. I am afraid I'm not that clear. We did, from time to time, ask for a breakdown of household expenditure. I'm not sure whether we asked for that

from everybody or only people in a particularly severe debt situation, it is my recollection that it was almost certainly the latter.
Q. Soumik, can we put back up, please, MACF0000176_009, which we're going back, then, to the Macfarlane Trust handbook to look this time at single payments.
Before we do that, can I just pick up a point that you raised in your witness statement and you've alluded to in your oral evidence and it's this: that you say you had a perception from the trustees that they thought that registrants should be able to manage on their regular pay, the inference from that being that they rather frowned on applications for single grants. Can you tell us a little about that?
A. It was not a perception from all the trustees. It's something that arose from time to time within the Trustee Board. Almost always it was not supported by the majority of the board. I think it possibly lay behind the idea that it would be better to increase the level of regular payments and reduce the level of single grants. But it was not, in my time, a majority view of all the trustees, or indeed all the registrants, which to be that balance.
Q. Can we go to page 8, then, of the handbook. We've got there "Trust Procedures", if we just look at that,

"Applications".
A. Yes, can we increase the size of it a little bit, that's better.
Q. Yes.
"We aim to keep everything as simple as possible. We have enclosed a form, but you do not have to use that ... you can write it a letter. The form exists in case anyone finds it easier than a letter and as a reminder of the information we need."
Then it refers on for further details, and then refers to the Trust's website. Then it says, "Staff Authority":
"For many of the ... common types of payment the Trustees have authorised ... staff to make immediate payments provided that the application falls within limits fixed by the Trustees."
Pausing there, presumably what is there being referred to is the single grant payments?
A. That would have been single grant payments, and some standard grants were certainly delegated to the staff, almost certainly the social worker. Possibly I was involved but I don't recall it.
Q. It says:
"These limits exist only to enable a large number of requests for help to be dealt with speedily without

having to wait for consultation with the Trustees. The Trustees of course retain discretion to go outside the limits if they consider the need justifies it and the Trust resources will permit.
"The staff can advise on the kind of help the Trustees may be able to approve, but they [meaning the staff] do not refuse any requests. Every application, which is outside the delegated authority of the staff is referred to the Trustees for their decision."
So these guidelines, sometimes referred to, certainly in later documentation, as the office guidelines, was that how they were referred to when you were at the Trust?
A. Yes, it was, yes.
Q. So the office guidelines set out maximum amounts that the staff could award and is it right that if an application came within those guidelines the staff would simply allow the application?
A. Yes, that is correct, and then we would report it, obviously, to the board when it met --
Q. If it fell outside the office guidelines then it would need to go up the line, as it were, to the trustees for decisions?
A. That's right, yes.
Q. And the trustees were not bound by the guidelines in the

office guidelines, they had a discretion to allow any amount that they thought appropriate?

A. Yes, yes.

Q. Then it talks about review. We don't need to look at that. Can we then -- sorry, can I just go back, in fact, to under "Staff Authority". Yes. I just want to ask you a question about staff authority in that first paragraph:

"The Trustees of course retain discretion [at the end of that first paragraph] to go outside the limits if they consider the need justifies it and Trust resources will permit."

So is it right to understand it in this way: that the staff simply say "yes" or "no" it comes within the office guidelines. The trustees, however, are looking at two things: they're looking, first of all, at need and, secondly, at the Trust resources. Is that how you understand decisions were made?

A. Sorry, what was the first you said -- trust resources, what was the first aspect you --

Q. To consider whether the need justifies it.

A. I'm just trying to see that in this paragraph.

Q. So it's the second line from the bottom of that paragraph. So the third line up:

"... Trustees of course retain discretion to go

outside the limits ..."

Do you have that?

A. Yes. Yes.

Q. "... if they consider the need justifies it ..."

That the first criteria I'm suggesting, and, secondly:

"... and Trust resources will permit."

A. Yes.

Q. So is that how you understand the trustees were making decisions, they were looking at need and resources?

A. Yes.

Q. Then if we go over to page 10, where there's more information about single payments, about:

"Following the Payments Review ... and ... consequent increase to Regular Payments, Single Payments ... are restricted to health related needs only."

Pausing there, can you recollect whether that, in practice, made a difference to the number of applications that were granted, the restriction to health related needs only?

A. I think there were things that you could stretch the medical needs requirement to, and they would be probably in the area of attending conferences, receiving support. I mean, for example, the support offered by Susan Daniels was not strictly related to a health need.

The benefits adviser assistance also was not strictly related to a health need. Unless, of course, you took it back to stress.

So whether or not grants that were outside strictly health-related needs could be approved by staff or had to go straight to trustees, I do not recall in detail.

Q. It would suggest that debt is something that wouldn't be paid off under --

A. No, debt would definitely not be agreed by the staff.

Q. No, but it would also suggest that it wouldn't be something that would fall under this single payment health-related need --

A. Exactly.

Q. -- scheme.

A. No, it wasn't a single-payment area at all.

Q. Would staff and trustees take into account stress when determining whether or not there is a health need?

A. I imagine that if the stress needs were great then it would be regarded as a health need, and there is probably evidence of Haemophilia Centre nurses or social workers writing a supporting letter on that situation with a number of cases.

Q. Then it goes on to set out the procedural requirements. So:

"Applications must be supported by an up-to-date

medical report and a supporting letter from the Centre or GP."

Then it says:

"Payments to widows and dependant children do not require medical support unless the widow/partner is also disabled."

So would you accept that to have both a medical report and a supporting letter is quite an onerous requirement on registrants?

A. My recollection is that towards the end of my tenure with the Trust, I don't recall that medical forms were completed. But, certainly, supporting information would have been requested which could have been anything from a letter from the Haemophilia Centre, social worker or nurse, or even from a GP, but because we specified health-related needs, there would have had to have been some indication of the health status of the individual at the time.

I cannot recall at this distance of time whether the forms that we used at the outset in the Trust continued to be used in that same format throughout.

Q. I think we'll come on in a few pages later to another reference to that, which suggests perhaps that the Macfarlane Trust might have sought at least some of those medical reports themselves. It continues:

"All single payments are made within the Trustee's discretion ... no rigid set of rules and regulations laying down the goods and services for which payments can be made. Equally, although the Trustees aim to be as consistent as possible, no one payment creates a binding precedent when considering similar requests."

Then a few paragraphs down, starting:

"In most cases the guidelines have been set to limits which allow staff to deal with over 80% of the requests received without further consultation with Trustees, and these requests can usually be cleared in under a week."

Is that accurate, as far as you can recall, by 2003?

A. Yes, I would say that was the case, yes.

Q. Then turning over to page 13, please, Soumik, "How to apply for help": grants only given for health related needs and then it sets out what to do in an emergency, routine applications in writing.

Then it says what the application must include:

"name and registrant number ...

"why you need help

"what you need

"how much it will cost.

"Please remember the following ... points:

"We are likely to be able to deal more quickly if

you have been specific about what you [want] with accurate costings.

"We usually require two estimates of quotes for work to be done.

"Remember, you can telephone us if you find writing letters ... difficult.

"... emphasise that if any need can be met from public sources [sets out examples], these sources must [usually] be tried first. If the official response is inadequate or involves unacceptable delay the Trust may then help."

In your witness statement you say that that's something that the Department of Health reiterated to the Trust on a number of occasions. Can you tell us a bit more about that principle and how it was applied by the Macfarlane Trust?

A. First of all, when the Trust was first set up it was made very clear that we should not make grants when a statutory service should or could be making those grants, and we tried to adhere to this. Most frequently, in cases of severe or terminal illness, if, for example -- and it was a common example -- then there was a need for adaptations to the property, as I'm sure you all know, these adaptations and approvals for them and budgets for them could involve a very great delay

and, if somebody is dying or terminally ill, they need the property adapted quickly, and that is why we did make grants in that area. We did make the Department of Health very aware that this was the situation. But that's how it happened.

Q. Then:

"Emphasis on health-related grants means that trustees will normally need to see an up-to-date doctor's report. Therefore, upon receipt of an application, you will be sent a consent form to complete and return to the office. This will be forwarded to your doctor so that confidential medical information about you may be released to the Trust.

"If it is possible for you to obtain medical report and supporting letters, these can be sent in with your application which will speed up the process."

It seems to be suggesting there that a medical report will be required but the Trust may take steps to obtain it themselves. Is that what you recall?

A. I think so, yes.

Q. We looked yesterday, and we can put it up on the screen if it will assist you -- we looked yesterday at a letter written by you in 2003 obtaining one of these medical reports. And the letter said to the clinician in terms:

"Any information you provide to us about the

registrant won't be passed on to the registrant."

Can you recall why --

A. Can you show the letter?

Q. Yes, I can show the letter, of course.

A. It would help, because then I can recollect the situation.

Q. It's TREL0000316_064. So if you go down. So it's:

"Dear, Dr Menser. Your patient ... has made a request ... for financial assistance ... present policy ... invariably health-related ... they receive ... up-to-date health information ... the form has been designed to be completed in less than five minutes ... all information on the completed report will be treated in complete confidence and will not be shared with the patient concerned."

A. This is a --

Q. Yes, I've got two questions in relation to this.

A. Okay, fine. Fine.

Q. The first is: why did the Trust consider it appropriate to be seeking confidential information, or to be seeking medical information about a registrant and then keeping it confidential from that registrant?

A. I can only explain that this is a letter that was designed and sent out regularly at the beginning of my tenure. I'm not sure whether, in later letters, we

would have said that the registrant should not have been informed. In fact, I think we would have, of course, always asked for the permission of the registrant to approach anyone for health-related advice. But we are looking back to a form that was probably created just after the formation of the Trust, early in 1988/89, and I think that data protection and user permission was very different in those days. I'm sure that this did not continue until the end of my tenure. At what point it changed, I don't know.

Q. Soumik, can you just show the date on that letter? It's 2 October 2002, so a year before you left the Trust.

A. Yes, quite. I am very surprised. It is a standard letter, and we should by then have recognised, particularly with the Data Protection Act, that that should not have been the situation. I can only apologise for not having spotted that that letter still had that paragraph in it.

Q. Can we go back then to MACF0000176_009 and page 13. So there we're going -- at the top of that paragraph, right-hand column:

"This will be forwarded to your doctor so that confidential medical information about you may be released to the Trust."

So you are there seeking consent for confidential

medical information to be released to the Trust, but what you're not doing, would you accept, is explaining to the applicant, to the registrant, that that information won't then be shared with them?

A. Yes, I do accept that. I know at some stage around this period, it was possible for registrants to come in and study their files and ask for corrections if there was anything that they were not happy with.

Q. Can we then go to page 12 of this document, please, Soumik. "Types of single payments."

So this is the information that is given to registrants about the kinds of payments that they can make; the kinds of payments that could be made. So grouped under "Health", and we can see there that that includes at the bottom there "Assisted conception":

"The Trust will contribute towards ancillary costs of assisted conception ... overnight stays and travel ..."

And so on. "Mobility". Then going down the page, we can see "Accommodation", "Education", and then right at the bottom, "Bereavement".

A. Yes. Do you have a question about it?

Q. Yes, I'm just coming to it.

A. Okay.

Q. Did the Macfarlane Trust seek any information from

registrants who were making these kinds of applications about their income and expenditure?

A. Not to my knowledge during my tenure.

Q. Would they -- when your staff team were assessing applications, were they simply looking at what had been asked for and what the grant guideline was, and if it came within that, they would grant it?

A. Yes.

Q. Didn't look at any outside material about -- from the census form, for example --

A. Yes.

Q. -- about household income? Didn't consider need, charitable need?

A. They would have looked at the guidelines. They would have looked at the registrant's file. A social worker would, if necessary, have called the registrant and talked them through what the situation was. If she had picked up at that time any other ancillary needs -- for example, benefits advice -- then that would have been something that would have been offered. But by and large, the actual giving of money related to the need and what was in the guideline as an amount.

Q. So do I understand that when applications were processed by the office, they were in fact looking to see whether or not the registrant could make out charitable need?

A. Yes.

Q. And would you --

A. We would --

Q. Sorry. Go on.

A. Sorry. We would ask whether there was any other application that they'd made. For example, if it was for adaptations to the house, we would find out from them and from their social worker whether there had been an approach to the local authority and the level of need. And --

Q. But you wouldn't be looking at whether or not they could afford their household income, for example; whether or not they had surplus --

A. No, we did not scrutinise household income, except in debt cases.

Q. Can we look, then, at the grant guidelines that the staff were using to make these applications. It's MACF0000011_031. This is the grant guidelines from October 2001. And if we go over to page 2 of that, you can see "Central heating, installation and repair". And it sets out the maximum that the staff can grant for a house or a flat for installation or boiler replacement, for example.

Then if we go over to page 6. For example, if we look at "Special chairs/beds":

"Subject to current maximum ... type of grant where the member concerned has HIV, a grant can be made towards ... a reclining chair ... supporting letter from an OT ... maximum £1,200."

These were the guidelines that the staff were referring to, are they?

A. Yes, they are.

Q. And how were these amounts set?

A. They would have been set by costing what was available on the market. I mean, a Parker Knoll-style reclining chair, we would simply have looked around and seen what the average cost was.

Q. And did it take account of regional variation?

A. I don't think it did at all. I'm not sure whether a Parker Knoll-style reclining chair would have been -- would have cost more or less in a different area.

Q. And what use did the trustees make of these guidelines? Although the trustees had a discretion to allow awards outside the guidelines, given that these prices reflect the average price of the -- whatever is being applied for, were they treated with -- were they quite compelling as to the amount that should be awarded, the trustees?

A. I think they accepted our research as regard to that kind of thing.

guidelines. They knew about the staff guidelines for payments. Every time an application came in from a registrant, it would either fall under the office payment guidelines, or it would go straight to the Trustee Board, and we would let them know what was happening to their application --

Q. Would you agree --

A. -- aware --

Q. Sorry.

A. -- aware that some people felt that we were not swift enough in responding. As I think it refers to earlier, most simple grants made straight from the office were paid within the week.

Q. Were you -- would you agree that it would have been helpful to disclose these average payments to registrants so they could pitch their application in a realistic ballpark, rather than spending time obtaining medical reports, GP letters, receipts, quotes, only to be aiming for something that was never going to be granted?

A. Well, I can't recall that being the situation at all. I'm quite certain that if somebody asked for a special chair or bed, they or their occupational therapist or social worker would be told the limit that the office could grant. These were not secret.

Q. So while the trustees had a discretion to, say, for example, pay £2,500 for a Parker Knoll-style reclining chair, you might say it's unlikely that they would have done. They would have, in most cases, said --

A. It's very unlikely. I do remember that during the time -- around this time, there was a special mattress that came in which I think is widely regarded as a special mattress which, when you lie down, it creates some sort of a form of your body so that it's easier to sleep in. That was a new area, one which had to be costed, and one which there had to be an OT recommendation for. That's just an example that comes to mind of something that happened during the latter years of my tenure.

Q. Why wasn't the -- why weren't these guidelines with the prices on, the average prices on them, provided to registrants?

A. I am not sure whether they were or not. I can't comment.

Q. We've heard from -- the Inquiry has heard evidence from registrants and also from Peter Stevens that they weren't -- during your tenure, in any event -- they weren't disclosed to registrants. Does that sound right to you?

A. I simply can't recall, I'm afraid. They knew about the

Q. So your recollection is that these figures were not secret, that they were common knowledge; they were disclosed?

A. Well, certainly -- I would have certainly thought, from recollection, that social workers or OTs in Haemophilia Centres would know about this. I'm not sure if registrants would know through hearsay, but they were certainly not secret, and they were given as a guidance.

Obviously, if the maximum that the office could agree had been exceeded in the recommendation from the OT, then it would have gone to the Trustee Board.

Q. Can we look at a different document now. It's MACF0000005_036. These are papers -- it looks like case summaries and papers that are provided for an allocation committee. If we go to the bottom of that page, "Main aloc meeting". Is that the allocation committee meeting?

A. That's right. Can we have the year, or is it not available?

Q. It's not available on here, but I think it's -- if we go to page 1, do we see it on "Benefit overpayment" -- (overspeaking) -- 15 Sept '98 --

A. That's it, yes.

Q. That would be the date of the meeting, would it?

A. That would be the date of the meeting, and that was

fairly early on in my tenure, within the first year.
Yes.
Q. So if we go over to page 4 of the document, please. If we just look at this case. Sorry, page 5. We've got there "Excess mileage/cooker", and then written in "Fridge-freezer mattresses". So are we to understand that those are the -- that's what is being applied for on 15 September 1998 by registrant number 1174? Is that right?
A. 1174, yes.
Q. Then the documentation doesn't have any names on it. What was the reason for that?
A. When you say it doesn't have a name on it, it's got a reference number, hasn't it?
Q. Yes. But what was the reason for not including names for papers that went to the committee?
A. Because we anonymised. As I'm sure I've said in my witness statement, when applications went to trustees they did not include a name.
Q. At then there's a summary of information there about the registrant, marital status, family circumstances, health circumstances, and then information about whether they have a car, housing, their employment status and then, a little bit further on, their benefits.
Where would this information have come from?

A. This would have come from the registrants themselves --
Q. So --
A. -- or their social worker. It would have been built up over time. The registrant files were kept as up-to-date as possible, and we did ask that if they experienced any changes in situations or status, that they let the office know. This didn't always happen. But we --
Q. So this comes from the file rather than the application for the grant?
A. Yes.
Q. Then a little bit below "Payments", it sets out what regular monthly payment the registrant is getting, and then it says, "Single payments", "Regular payments" and "Winter payments", is that the total that this registrant has had over the period that they've been with the Macfarlane Trust?
A. I can only assume so.
Q. What's the relevance of including this in the information going to the trustees?
A. I suppose at the outset of the Trust, this was what the trustees requested, and this is certainly a format devised before my time.
Q. When you -- ooh, sorry. When you were in post and trustees were making decisions about whether to grant applications, were they considering income, the income

and expenditure of a particular registrant to try to assess whether or not they had a need for the grant?
A. No, I don't think so. They simply wanted to see the situation. I don't remember any grant ever being withheld on the ground of -- the grounds of what the income was, whether that income was from the Trust alone or from the Trust and benefit system, whether or not they worked. We did not look at the overall income and expenditure of the individual, except, as I've said previously, when there was a serious debt problem.
Q. So how was it that the trustees, insofar as you can recollect, assessed the need for a particular grant?
A. I'm just looking at this particular one as an example.
Q. So if you --
A. What he's doing is he's in a fortunate position to be able to do one day of ambulance work, which gives him great personal satisfaction, but the Motability car allowance is limited, and he would push -- as he is saying here, he has to pay Motability up to £500 for a period of three years so that's £150-something a year, and he is asking for a grant to help with this because clearly he doesn't gain any income from doing this ambulance work, it is entirely voluntary, but it does impact on his Motability mileage. So he's asking for a grant to cover this, and I'm pretty sure it will have

been approved.
Q. Then if you go over the page, we can see what happens over the page. There's then information about the second and third requests. The second request being a cooker, third request being a fridge-freezer:
"... moved into a ... house earlier this year ... inherited a cooker ... hardly works ... both are essential to his health. The fridge has to work correctly because he needs to store ... Factor VIII as well as ... HIV medications."
Then the fourth request, which is the mattress, I believe is:
"... mattress is in a dreadful state due to the night sweats ... unhygienic and has to be replaced. With all his other expenses due to the move this is just one more thing he is having difficulty in finding the money for."
Then:
"This request has been referred from the last mini alloc. Trustee also required a list of members single grants."
That is provided in the following page, we don't need to go to it, but there's a breakdown of all of the single payments that he's received over the year.
Then it summarises the amounts that are being

requested, and then there's a recommendation. Is that recommendation the recommendation of the Allocation Committee or is that the recommendation of the staff team that goes to the Allocation Committee?

A. It's the recommendation of the staff team which sends it to the Allocation Committee.

Q. So the recommendation is:

"To make [the] grant for the excess mileage ... essential part of his life ...

"... make a contribution towards a cooker and fridge-freezer if he is unable to secure funding for these through a community care grant ..."

It notes that Jenny Jackson, who we know from your previous evidence is the benefits advisor, is currently applying for one, and:

"To make a grant for the mattress due to issues of hygiene."

A. Yes.

Q. So what's the process by which staff come to make these recommendations? How does one assess the particular need for these items, if they're not taking into account financial need? How do they --

A. Because they would have received the information almost certainly from a Haemophilia Centre social worker in this case. That's my recollection of this particular

one, and they would not -- it would not be part of the staff team's responsibility to look into the financial situation of the particular registrant. They would know how much regular payments they were getting. They would know how much benefits, if they were receiving benefits, they were getting because this would all be on the file. They would actually also know the number of single grants that had been applied for and granted.

So they wouldn't need to do that. They wouldn't need to look for any kind of financial justification, and neither did they.

Q. How then would you or your staff team, looking at these, decide when to allow -- when to provide the grant in full or recommend that a contribution is made? Presumably, in both cases, there's a need for the item. The question is just how much is going to be given. Was there any guidance that help the staff?

A. Well, a cooker and a fridge-freezer, for example, are things that the local authority, or I think it's sort of -- or government, community care grant, you can apply for from the local authority under that heading, just as you can apply for adaptations in the house. So it would be a responsibility to first ensure that that application had been made or, as is apparent here, Jenny would -- or the benefits advisor in post at the time

would apply on their behalf for one.

If that was turned down, and it was obviously an essential need, then the full grant would have been given.

Q. Here the recommendation is if the grant is turned down, to make a contribution towards a cooker. How did staff determine who would get a contribution and who would get the full grant when the item that --

A. I cannot remember the details of this case, but I'm quite certain that if the need had been to pay the full amount for the cooker and the fridge-freezer, if he was unable to apply for or get any community care grant, then we would have paid for the whole lot, but I don't recall the outcome.

Q. Was there any guidance that you can recall that set out how trustees or staff were to assess need on these kinds of applications?

A. I think, as I was hoping to make clear, these grant applications, as has certainly been an example, would come through the Haemophilia Centre social worker, or possibly on occasions the Haemophilia Centre nurse. It would not have come directly from the registrant or very, very rarely. If the person was looking for a holiday grant, for example, even that we would have expected there to be an accompanying recommendation from

a Centre social worker, or a local authority social worker, working with the family.

In other words, we didn't assess the need in the staff group. It would have been a need which would have been identified by an external social worker, and there were many occasions when, as a result of that request, not in this case, Jenny or Fran, or social worker and benefits adviser, and on rare occasions also Susan Daniels, the financial adviser, would have visited a registrant and talked them about the situation.

Now this would not have been necessary in this case because, apart from applying for the community care grant, this was an obvious need.

Q. Do I understand your evidence to be this: that if an application was supported by a social worker or a nurse or indeed the local authority, that would be sufficient to establish need for the Trust and that those applications --

A. Yes.

Q. -- should have been granted?

A. If there was any reason to require more information then the Trust staff would become directly involved.

Q. Do I also -- I'm sorry.

A. In this situation, it would become immediately apparent that the cooker and fridge-freezer could be paid for

through a community care grant and possibly the centre from which this request comes either didn't have or didn't recognise the need to approach the local authority for such a grant.

Q. Do I also understand your evidence to be that there wasn't any guidance to help trustees or staff to assess need because, in fact, they -- I think you were saying that the need would have been established by the supporting clinician or social worker who is supporting an application?

A. That's right. If more information was needed, if this was immediately apparent, then there would have been contact from one of the office staff and possibly a visit. I think it's quite clear here that with the application must have been the obvious need to ensure the local authority had not been approached for these things before a grant was given.

Q. When applicants were successful, did the Macfarlane Trust provide vouchers instead of cash or cheques to registrants to purchase items?

A. No, I never remember such a thing being done.

Q. I've just got one more question before we break for lunch and it's this: you say in your witness statement that later trustees thought that the Macfarlane Trust was too generous during your tenure, and I just wondered

how you heard that and what you understood that to mean.

A. I think that sometimes the trustees did feel that I would err on the side of generosity if I had any involvement in making a grant, which was rare. But they knew that when I spoke about things, such as the bereavement project, or alternative therapies, or the need for more support in other ways than financial, that I was -- they felt I was being a bit over indulgent, I think. Some of that was hearsay, in fact I suppose all of it was hearsay, really.

Q. When you say all of it was hearsay, do you mean -- what do you mean? What are you referring to?

A. Um ... well, I mean I knew that it was a general climate in the Trustee Board that perhaps I was encouraging being over-generous in our responses. I don't believe that was the case, but I think it was something which was felt and, after I had retired from the Trust, I later heard from a member of staff who had retired that there was some sort of an investigation into the levels of grants that I had recommended. I don't recall recommending many grants at all. I don't think it came to anything.

MS SCOTT: Sir, it's just past one o'clock.

SIR BRIAN LANGSTAFF: Do I take it that you were personally aware that, given broadly the same facts, a number of

the trustees, perhaps even the majority, would have been less generous than you would be inclined to be?

A. I don't think it was the majority. I think it was an opinion that was abroad, and yes, I think so.

SIR BRIAN LANGSTAFF: Thank you very much. Well, we'll take a break now until five past two. So five past two. Same rules apply, of course, and I look forward to seeing you back at five past two.

(1.05 pm)

(Luncheon Adjournment)

(2.05 pm)

MS SCOTT: Ms Hithersay, can you hear and see me?

A. Yes, I can. Thank you.

Q. Excellent. Just picking up on some evidence you gave earlier about debt, when applications were made to clear debt by applicants, is it right that those would all have been decided by the trustees because they fell outside the office guidelines?

A. Yes, yes, that's correct.

Q. Your recollection, I think, is what you said in evidence earlier, was that often those applications were dealt with by way of loan rather than by way of single grant?

A. That is correct.

Q. Can you recall whether or not there was any policy or any written guidelines for the trustees setting out when

applications for debt should be acceded to, and in what form, ie loan or grant?

A. No, I can't, because I don't believe there were any guidelines. It's my recollection, from my understanding, that it was equity share that was suggested originally, and in very early cases, and that subsequently, we received a recommendation from our solicitors, Paisner & Co, that we should either give a grant or a loan with a charge on the property, and that we were, under the trust deed, able to do either of those things. Equity shares, I don't believe they ever completely stopped but they were not the best way to deal with the situation, with hindsight.

Q. Soumik can we look at MACF0000065_059. This is a letter from you -- sorry, not from you, from Macfarlane, to the, I believe they're your auditors, Pinkney Keith Gibbs, about loans and secured advances, and it says in the second paragraph:

"Following the above review" --

The first paragraph:

"Further to your letter ... I went through the Nominal ledger accounts [this is from Rodney Shepherd, the finance man] in some detail and have also reviewed the entries on the individual Purchase Ledger accounts.

"Following the above review, and having checked the

outcome with Ann we now have three schedules with details of the individuals involved in the three types of Loans made."

Then he sets out the schedules. Now, the first schedule, which I'm not going to take you to is the equity share schedule. The second schedule which I am going to take you to, is -- at page 3, please, Soumik -- is the legal charge loans. If we can make that a bit bigger we can see at the top "Legal Charge Loans", and then the value is on the right, and then there are three legal charge loans, ranging between £6,000 and £10,000. Are those loans that were secured on property by way of a legal charge?

A. If it comes under the heading of "Legal charge loans" then yes, they would have been.

Q. Then if we go over the page to the third category of loans, and we've got there "Exchange of Letter Loans" and we can see down the right-hand side there are number of loans there, ranging between £2,048 at the bottom, up to just £4,775, and we can see in the middle column, reference, it says, "From ADVANCES" on two of those loans. Would we understand or are you able to tell us whether or not that means the other loans are not from advances or would all of these exchange of letter loans be from advances -- from advances on regular pay?

A. No, I think only the ones where it says, "From ADVANCES". The others would have been loans granted as a loan or with some kind of a repayment schedule attached.

Q. So the amounts of these loans are amounts -- they are similar amounts, aren't they, to amounts that might be given to somebody by way of grant?

A. They are.

Q. Was there any guidance or any policy which set out how the trustees determined whether or not something was given as a grant or given as a loan?

A. To the best of my knowledge, there was no policy. There would have been a discussion at Trustee Board level. It might have been that the original approach from a social worker or the registrant themselves suggested that they would like it as a loan, and they would like to repay it. It might have been that it was decided that it would be best to -- for example, if you look at the 4,775 one, to do with a car purchase, I think it was likely that there was no Motability element to which that person would have got a car. She would have clearly needed a car, and so she would have applied probably for a grant -- a regpay advance that she would have paid through regpay in order to obtain a car.

I have to say this is supposition and recollection,

I'm not certain but very often, the idea of a loan related to regpay came from the registrant themselves or the registrant in discussion with a social worker.

Q. The Inquiry has received evidence from those that have made applications, and there's been confusion as to the circumstances in which a loan or a grant has been given. There's a lack of clarity as to when either one or the other is given by the trustees. Is that something you were aware on when you were at the Macfarlane Trust, that the registrants didn't understand the decision-making process in respect of loans?

A. I don't think, from this standpoint of time, I can recollect either, but these would all have gone to the Trustee Board, and they would have considered the elements, and certainly, in some cases, the suggestion or the request would have come direct from the registrant that they wanted -- they were asking for a loan, they weren't asking for a grant. You just said that that could have been a misunderstanding on the part of the registrant. I can't really comment on that.

Q. I am not suggesting that somebody asked for a loan by mistake; I'm suggesting that people -- when people got the results of their applications back, that they -- it wasn't clear to them and they didn't understand why, sometimes they were given a grant and sometimes they

were given a loan.

A. I think without specific examples, I can't answer that.

Q. I'm going to ask you some questions now about the Partnership Group.

A. Yes.

Q. I understand from documentation and your witness statement that this came out of the Strategic Review; is that right?

A. No, there was a Partnership Group that existed in some form before that. I'm not quite sure how it arose but certainly it arose during my tenure. It was an opportunity for the registrants to meet the staff and, in the early stages, there were representatives from certain groups of registrants and it was so that they could exchange views with the Trust on certain matters and what happened was that I think there was a phrase somewhere about it growing like Topsy, so that all manner of people felt that they should come. Indeed, I think probably at the point of the start of the Strategic Review, we recognised -- we more or less threw it open at one stage and the numbers became too great to deal with.

Following the Strategic Review, the Strategic Response Group recommended that we form a new Partnership Group with specific representation from

particular areas of registrants and others. That's my recollection.

Q. Soumik, if we look at MACF0000088_028, it's a meeting of the Partnership Group, notes of a meeting held on 23rd September 1999, and you were attending that meeting. Then if we go halfway down the page, notes of a meeting held on the 14th May 1999:

"Issues arising in response to the Notes of the first meeting ..."

Do I understand from that, that the reconstituted Partnership Group, after the Strategic Review, started meeting on -- the first meeting was 14th May 1999? Does that sound right?

A. That's certainly what is suggested there.

Q. Does that sound right to you?

A. I'm not sure whether this is when it was entitled and had a different representation, the new Partnership Group, or whether this was a Partnership Group that came in before that.

Q. It may be, if we go over the page to page 2, it may help. "Matters arising" at the bottom of the page, "Membership and Representation":

"The issue of the role of the group, and its remit was discussed at some length. It was agreed that whilst members recognised the need for more formal 'user

involvement' in the Macfarlane Trust, the Partnership Group had been set up as a means of response to those recommendations in the Strategic Review that required multi-agency participation in implementation."

If we go over to page 3, we can see the recommendations for the make-up of the group:

"After considerable discussion it was agreed to recommend that the group be made up as follows ..."

It sets out the different representative categories of those in the group. Then it says:

"It was agreed that Ann and Fran would identify and invite women to fill the roles of Partners and Positive Women."

Does that prompt your memory?

A. It was my memory that I was -- I think this was a group that was formed after the Strategic Review, because it refers to the Strategic Response Group and I think that came under -- soon to be known as the new Partnership Group. I believe there was a group before that. My recollection is that there was a group before that and that that group became too large and unrepresentative of all constituents. That's my recollection. I'm sorry if I can't be more specific than that.

Q. What was your --

A. Certainly, this was the Partnership Group, in inverted

commas "new" Partnership Group, that arose when it -- I think it became amalgamated but with the Strategic Response Group.

Q. What's your recollection of how the Partnership Group functioned and the advantages or disadvantages to the Trust in having this group?

A. The advantages to the Trust was -- the aim was better representation of the views of registrants themselves. Certainly, the encouragement of representative groups pushing forward their views of how the Trust worked and how it worked to meet their needs was what was being aimed at.

Q. Was it successful, in your view?

A. I think it was. I'm not sure whether it ever joined with or was part of the actual Conferences Working Party, but certainly the organisation of conferences was, from my recollection, a part of the role of the Partnership Group and making it possible for different groups of registrants to meet and share experiences and identify needs was a significant part of what the group did.

I believe that when it became -- when it was more involved with other organisations, and when the group met with the hepatitis C groups, as well, the original value to some of the registrants was felt to be watered

down and membership decreased. This is -- I'm afraid this is from recollection. The original aim changed over the period of the lifetime of the Partnership Group or groups.

Q. Was the response to that to then separate out the groups so that those outside agencies would still meet with the Macfarlane Trust but not within the context of the Partnership Group?

A. Not within my tenure.

Q. I'm going to ask you some questions now about user trustees. I understand from your witness statement, is this right, that at the time you began employment at the Macfarlane Trust, there was not a user trustee in place because, at that stage, the Charity Commission guidance suggested that that was not appropriate for a grant-giving charity --

A. Yes, that was the case.

Q. -- and that you were involved in the Charity Commission's process at re-looking at that guidance --

A. Yes.

Q. -- and that the Charity Commission guidance changed at some point during your tenure?

A. Yes.

Q. Were you enthusiastic about user trustees?

A. Definitely.

Q. Why?
A. Because I'd worked with them before and seen the value to the balance of the Trustee Board and felt that it was a very effective way of the whole Trustee Board being able to more clearly understand and respond to the needs of the registrants.
Q. So you've given -- in your evidence this morning, you were describing that there were people on the board already who suffered or who were -- people on the board already with haemophilia, albeit they weren't user trustees --
A. Yes.
Q. -- so there was a degree of knowledge already. But the way you've described the board, particularly when you arrived, did you particularly think that this board could do with user trustees? That's not a very elegantly put question, but ...?
A. I understand that in the early life of the Trust, there had been a user or user trustees on the board, and then the -- certainly the Charity Commission guidance changed, and also I think that some of the other trustees felt that it was difficult. And particularly where money was being spoken of, it was difficult.
And there had been -- I think it had been quite welcomed by the Trustee Board when they could no longer

appoint user trustees. However, as the guidance changed, we did introduce user trustees again.
Q. Was that something that you particularly pushed for then, in light of the lukewarm view of the existing trustees to user trustees?
A. Yes, it was. It was because I came from a background where user trustees had been people who used the services of the charity, rather than received money from the charity and that was, I think, the Charity Commission's distinction which enabled the user trustees not to be continued with.
As I recall, the discussions with the Charity Commission were based on the fact that, actually, there is not a significant difference between giving someone a grant to obtain a service and providing the service through -- directly through the charity and that the benefit of users was, as I've said, to enable the Trustee Board to take a balanced and more clearly understanding view of, in their terms, the beneficiaries.
Q. The documents show that there was an advertisement put in in the newsletter at Christmas 2000. Does that accord with your recollection, in terms of the time frame?
A. Yes, it does.

Q. And were there sufficient -- was there sufficient interest from the registrant community to take up that post; take up those roles?
A. Yes.
Q. It was something, was it, that the registrant community, the beneficiary community, welcomed and thought was a good idea?
A. Yes, I think so. This was advertised through The Haemophilia Society, and I think it could have been in our handbook, but The Haemophilia Society was to be responsible for actually nominating those user trustees.
Q. What was the attitude of the existing trustees to that? Were they reluctant? Welcoming?
A. I think they were ... what's the word? I think they were doubtful because they saw a major part of their work as being connected with money, and they didn't think it right that user trustees should be involved in any discussions about distribution of the funds.
Now, it had been understood from the outset of proposing user trustees that they would not be involved in the allocations of grants part of the meeting because that would be creating, for them, a conflict of interest.
Q. Given how important funding decisions generally were to the Trust, do you think -- is there a sense in which the

user trustees were second-class trustees? Kept out of some of the decisions? Did you get a feel for that?
A. I think the user trustees -- from my recollection, the user trustees agreed that it would not be appropriate for them to be discussing detailed grant applications on behalf of other registrants.
I think where wider policy areas came in, like whether we should apply for more money from the Department of Health or particular projects like the bereavement project, they would have been involved in the discussion. It was personal payments to individuals that they obviously would know.
Q. Did you get any sense, or did you see anything that might suggest that, as user trustees, they were in some way second-class citizens, if I can put it that way, on the Trustee Board?
A. I don't think so, whilst I was there, no.
Q. What's your recollection of -- well, if the aim was to bring something new to the board, a different perspective, some balance, what's your recollection of how that played out?
A. I think some were suspicious of it and others welcomed it. I can't be specific.
Q. Do you recall any discussion about trying to ensure that different communities of registrants would be

represented on the board through user trustees? For example, if I can put it this way, primary beneficiaries, the infected person with haemophilia, the widow community, for example? Was thought given to that?

A. No.

Q. No?

A. No.

Q. And what is your understanding of the definition of a user trustee? Is it someone that uses the services of the charity, or can it be wider than that and include, for example, a family member who isn't a beneficiary of the charity but could be --

A. The trustees would have implied that they would have been a beneficiary of payments from the Trust.

Q. We heard evidence yesterday -- moving on to a new topic now. We heard evidence yesterday from Peter Stevens.

We heard evidence yesterday from Peter Stevens about emails passing between him and Mr Clarke, another of the trustees on the board, in which Mr Clarke described some or all of the registrants as "the great unwashed".

Do you recall being informed about the existence of those emails at a meeting with the Birchgrove board in a hotel prior to a Partnership Group meeting?

A. No, I don't.

Q. Do you have any recollection of those emails and the fact that they existed?

A. I don't have any recollection of knowing of their existence.

Q. I'm going to ask you some questions now about the Macfarlane Trust's relationship with the Government, and in particular the Department of Health.

SIR BRIAN LANGSTAFF: Let me just ask a question, if I may.

MS SCOTT: Yes.

SIR BRIAN LANGSTAFF: To what extent does that use of that phrase by that person in that email surprise you?

A. It does surprise me.

SIR BRIAN LANGSTAFF: Thank you.

A. It also distresses me.

MS SCOTT: Did the Macfarlane Trust have regular meetings with the Department of Health during your tenure?

A. Yes.

Q. And were -- did the Eileen Trust also have regular meetings with the Department of Health?

A. It's my recollection that they were usually part of the same meeting, but we simply stopped talking about the Macfarlane Trust and moved on to the Eileen Trust.

Q. And can you recall how frequently those meetings took place?

A. I understand from all the papers that I've read that it

was quarterly. My recollection is that it may not have been quite so frequent.

Q. And who would they typically be attended by? Who would go to those meetings?

A. Almost certainly the chairman and myself, and occasionally the finance officer, and occasionally the treasurer. Usually the chairman and myself.

Q. And for the Department of Health, it would be attended by civil servants from the blood policy unit --

A. It would be a nominated person which changed over time.

Q. And were those meetings all minuted?

A. Oh, yes. By the Department of Health.

Q. And was it standard practice for the Macfarlane Trust to get a copy of those minutes afterwards?

A. Yes.

Q. So would you expect the Macfarlane Trust to hold a full or pretty much full copy of the minutes of all of those meetings with the Department of Health?

A. Yes.

Q. I'm just going to read out a very short part of your witness statement to you, and if you want it up on screen, then I will -- we can, of course, do that. But in your witness statement, you are, in fact, talking about the Eileen Trust, and you're talking about whether or not the Eileen Trust could have done more to

advertise its existence, which is something we'll come on to in a moment.

But you say this:

"It wasn't the role of the Trust to advertise or promote or campaign in any way."

And it was this part I just wanted to get your views on:

"We simply administered the fund that the Department of Health had given to us. We had no independent existence as an organisation or a charity. In common parlance we were a quango, carrying out work on behalf of the Department of Health. As I have explained above, the Macfarlane Trust had been set up to administer a Government fund and nothing more."

Is that how you recall and how you saw the relationship between the two, between the Macfarlane Trust and the Department of Health?

A. I should say that I -- obviously, when I stated that in my witness statement, I overlooked the fact that we were a charity. Having worked in charities for a large part of my life before that, this was a very different set-up, which is why I used the word "quango".

I certainly think that the Trustee Board when I joined very much felt that we were administering a fund that had been provided by Government through the

Department of Health.
Q. And did that attitude come through, then, in how they -- in the information that they expected from the Macfarlane Trust? Did they expect you to report to them with your spending plans and so on?
A. We used to discuss a budget every year. We used to seek project funding for particular activities that might have fallen outside the particular budget year or spending plan, like, for example, both the reviews and like, for example, the assistance which was bringing our computerised systems up to date, and later getting new computers, again, because of the -- what was perceived then as the Y2K problem. So there were areas that fell outside what we had discussed in the budget preparation meetings, yes. So we would have presented a project application to them. But we certainly primarily saw them as our main source of funding, our only source of funding, for investment.
Q. Was the Macfarlane Trust -- did the Macfarlane Trust have to effectively seek the approval of the Department of Health for their policies and spending plans?
A. I'm not sure about approval as such. What we had to do was to prepare and present a budget, a financial plan. And then that would go through to the relevant part of the Department, and they would approve it, and

I think -- I don't remember them ever not approving it -- there might have been a delay in payment.
Q. So when you say that the DoH, certainly in the early years, felt that you were administering a fund that had been provided by the Government, how did that -- why did you come to that view? How did that show itself?
(Audio disruption)
A. I don't think it was necessarily the Department of Health that held that view. It was certainly the trustee interpretation of the Department of Health's view.
Q. So the trustees' attitude to the Department of Health was to seek approval, was it, of particular policies, to run things past them, to make sure that the Department of Health didn't have any difficulty with the approach they were taking, and so on? Was that the general approach of the trustees?
A. Um, I wouldn't have said so. It was very much having a discussion meeting which was minuted, at which we brought up, for example, the changing need of registrant post-1997, or the need for a 10-year review, or later a 15-year review, that kind of thing. They didn't agree or disagree policy areas.
When we were making loans, we certainly sought the approval of the Department to do that and their legal

department said, "Yes, this is okay". I don't recall and I wasn't there when the first equity loan arrangements were made so I don't know whether that was floated past the Department or not.
Yes, we provided information, they asked questions. I don't believe they ever made any policy guidelines or commented on our policies. From that aspect, we were an independent charity but we were also fulfilling their direction.
Q. Fulfilling their direction. What do you mean by that?
A. Spending the funds that were allocated and their direction was that they wanted regular reports on the activities of the Trust --
Q. Was there ever --
A. -- and --
Q. Sorry.
A. -- those took place in meetings with them, sorry.
Q. Was there ever -- did you ever encounter any -- the Department -- I think you said they didn't agree or disagree with policies, is that right? They didn't comment on or have input into --
A. I don't recall that.
Q. They didn't have any input into any of the policies that Macfarlane drew up or applied?
A. I don't think so.

Q. The Inquiry has seen minutes of board meetings, and certainly at least one during your tenure which we can go to if it's helpful, but where -- Macfarlane Trust board minutes, where Department of Health officials or civil servants have attended. Do you have a recollection of that happening during your tenure?
A. Was that Sue Bader Malik?
Q. Let me find it it's MACF0000011_003. It's Mr Robert Finch.
A. Yes, I do recall Robert Finch attending. I don't recall the context of why he was there but there was certainly nothing -- no reason why from time to time one might not have joined our meeting.
Q. We can see there 28th May 2002, and you can see where Mr Finch in attendance.
A. Yes. There certainly was a period, and it could have been about then, when we had a finance trainee from the Department join us on a six-month secondment. It could have been that Robert Finch was connected with that, but I can't recall the detail.
Q. So you say there's no reason why the Department of Health couldn't attend board meetings. What was the benefit of that attendance?
A. I can only assume that they wanted a different viewpoint of what was taking place at the -- in the Trust at the

time.
Q. Do you --
A. I cannot remember, I'm afraid.
Q. Do you recall whether the Department of Health got the minutes of the Macfarlane Trust board meetings as a matter of course?
A. No, I don't believe they did.
Q. I'm going to move to a new topic now. Soumik, can we have DHSC0004101_048. This is a letter dated 29th August 2003 from Dr Hay to you, and he says:

"I am very grateful to you for sending us your list of patients with haemophilia who have died and who were HIV positive so that we could reconcile with the National Haemophilia Database and identify any potential discrepancies."

Then he goes on to say what he found, that the database had not been notified of 16 deaths and they've amended their records, and that in two cases registered with Macfarlane Trust there was -- they hadn't been notified, the UKHCDO hadn't been notified that they had HIV, and then goes on to look at the circumstances of those two cases.

Then picking up towards the end of that paragraph:

"When we examined your results, we found that we had records of 70 HIV positive patients who are dead but who

do not appear in your list. Presumably either they or their relatives did not register with The Macfarlane Trust or possibly they died before the Trust was created."

Then sets out some details of those 70 patients.

Then we can see your response on 4th September 2003, which, Soumik, is HCDO0000612_003. This is your letter in response, 4th September, "Dear Dr Hay", and you thank him in the first paragraph and then a discussion about the two patients who may or may not be HIV positive. Then the paragraph starting:

"It would also be very useful to have names of the 70 deceased patients not recorded on the Trust's database. This is a large number of people not to be recorded and we need to investigate why and try to trace their families. Even if these patients died before the Trust was set up, payments should have been made by Government to their families. We will certainly pursue the matter on their behalf."

SIR BRIAN LANGSTAFF: I think perhaps the emphasis there might be "should be made by Government to their families", as opposed to "should have been made". The sense I get from this is that the patients themselves wouldn't have got the money, but their families were entitled to, under the deed.

A. Yes.
MS SCOTT: A couple of issues arising from this, this is dated 4th September. You leave the Trust six or seven weeks later.
A. Yes.
Q. Can you recall what, if anything, you did in response to the tracing of those 70 families?
A. I would certainly have made Peter Stevens aware of it. The extent to which I would have delegated action to one of the members of staff, I cannot at this stage recall.

Our means of knowing about registrants of the Trust were passed to us by the Department of Health and, most often, through the actual Haemophilia Centres. So I am surprised that it's a very large number, very surprised that Dr Hay didn't apparently know about it, know about some of them. It obviously should have been followed up, and I hope it was but, at that time, there was a great deal going on in the Macfarlane Trust, and I probably didn't put that as a priority. Peter certainly would have known about it.
Q. Was there a concern at Macfarlane that, given there was a relatively large number of individuals who had never registered, that there may still be some individuals out there, living, who weren't registered? Is that something that the Trust considered?

A. Yes, it is a possibility. I would be very sorry if there were children who had been infected, and had -- or indeed widows who had been infected, who had not benefited in any way from the Trust.
Q. I'm going to ask you --
A. I see that this is copied to Peter so he would have known about it, and also Mark Winter, and Mark might have had an idea of how we could pursue this.
Q. I'm going to ask you a handful of questions now about the Eileen Trust, and then The Haemophilia Society.

Can we look, Soumik, at EILN0000016_052. This is the Eileen Trust Annual Report from 2002. I just want to get an idea of the numbers of registrants during your employment with the Eileen Trust. So if we can go to page 2 of that document, please.

Under the "Trust's operation":

"The trust provides assistance to ten registrants (four of whom are single), to two people who were infected by their spouses who had been registrants before their deaths, and to two children who were infected in utero. Assistance is also given to nine families of deceased registrants. Within all these groups there are 12 children aged 18 or under and a further five young people up to 25 years old who could receive financial help from the Trust; four of these 17

young persons are orphans. Included in these numbers are three who became newly-registered with the Trust in the course of the year. There is one further registrant, also below the age of 25, with whom the Trust has been unable to establish contact for several years."

Then towards the bottom of that page, where it says, "Financial help continues to be given in three forms", and we see there:

"Regular payments are made monthly to 25 individuals or families."

Then over the page:

"Single payments are made in response to specific requests for help ..."

We see halfway down that paragraph:

"During the year 69 individual grants were made, varying in size from £100 to £5,790 ..."

Then the paragraph after that "winter payments, which are in effect supplements to regular payments" were made during the year, 12 of those in total.

So that was in 2002. Did the figures, did the numbers broadly stay the same during your tenure?

A. Yes. I think it likely that perhaps one or two new registrants were found during that time but I cannot recall the detail.

Q. In your statement -- well, is it right to understand that the numbers of those that registered with the Eileen Trust were lower than the Department of Health had anticipated; is that your understanding?

A. Yes, I think it likely. Yes.

Q. In your witness statement you suggest -- well, you speak about some of the reasons for that. In particular, that people may not know that they are infected with hepatitis C via contaminated blood and, equally, even if that's the case, they may not know about the Eileen Trust.

Can I take you to a document which perhaps throws up another reason. Can we go to EILN0000009_011. This is a letter dated 16th March 1998, and if we go to the second page, we can see it's a letter from you. If we go back to the first page, we can see it's to Derek Dudley from the NHS Executive, and you say:

"As you ... know, we receive all information about the Eileen Trust members from The Department, and not all those who have received a payment from The Department chose to get in [touch] with the Trust ..."

You then say, at the penultimate paragraph of that page:

"Whilst The Department of Health may have made payments to other people since 1995, we have only

registered three since that time, so you will need to check to see how accurate our figures are now."

So is it right that there were people that received capital payments from the Department of Health who never registered with the Eileen Trust to receive any further payments?

A. Yes, that is right.

Q. You never had their details because they never -- because they were never passed on to you by the Department of Health?

A. Yes, that's correct.

Q. Do you know whether -- can you recall whether any action was taken after you sent that letter, whether the Department of Health made an attempt to contact those people to check whether or not they wanted to get in touch with the Eileen Trust?

A. I am afraid I don't know. I don't think we checked that they checked. I think it's important that, whilst everyone who became infected with HIV through blood products felt greatly and deeply sensitive about the infection, some of them, both in the Eileen Trust community and indeed in the Macfarlane Trust community, particularly widows, felt that the stigma of HIV was so great that they did not want any further links, and I'm not sure today whether that is still the case but it

certainly was the case at the stage that I joined. There was a great sensitivity about the stigma related at that time to (inaudible)

I also think that, as it says somewhere in all the papers, it would have taken an alert haematologist in a hospital when someone was diagnosed with HIV, to relate it in any way to their treatment, either by large blood transfusion or tissue transfer. It wasn't something that would have immediately come to mind of medical practitioners because there were a range of other ways in which people could have been infected with HIV, and I think it's important to remember that the responsibility of the Department of Health to make haematology departments keenly aware, and the whole medical profession aware, that when somebody came to them and was identified as being HIV positive, that their background was explored if it wasn't immediately obvious.

Q. Soumik, you can take that down. Can we put up CGRA0000852. You can see this a letter from you on 28 November, and it's to a registrant of the Eileen Trust. I just wanted to take your -- draw your attention to the big paragraph starting:

"Charles Lister, our contact at DoH, has just been in touch with me to say that their legal department have

advised that because you became infected with HIV in Scotland, in order to receive the second payment from the Macfarlane (special payments) (No 2) Trust ..."

That's the capital payment, is it, from the Government in respect of his HIV -- the HIV infection:

"... the 'Undertaking' you would be asked to sign would be the Scottish 'Undertaking', not the English one."

Then you say at the bottom of that paragraph:

"You would be entitled to £23,500 that you would have received in 1991, had you known about the Trust at the time."

So is this right, that throughout your time at the Eileen Trust up until 2003, any new registrants coming on to the scheme, the Eileen Trust scheme, still had to sign the waiver that was being signed by registrants in 1991 in exactly the same terms; is that is correct?

A. Yes.

Q. So for those under the English scheme, they were still having to sign a waiver, were they, that included not only HIV but hepatitis C?

A. That is my recollection, yes.

SIR BRIAN LANGSTAFF: Just to be clear for the transcript, that's 28 November 2000. You didn't give the year.

MS SCOTT: Ah, yes. 28 November 2000.

SIR BRIAN LANGSTAFF: And anyone who looks at the document will see it, but for those who don't have access to the document, that's the date.

MS SCOTT: Yes.

Peter Stevens gave some evidence about the Eileen Trust yesterday, and he said two things. He said, first of all, that it was run like a mini Macfarlane Trust. And, secondly, he said that he regretted not identifying earlier the differences between the two trusts. And I wondered whether or not you would agree that the Eileen Trust was run like a mini Macfarlane Trust?

A. I think we certainly based our level of grants on the Macfarlane Trust grants. There were areas where people in the Eileen Trust were invited to join the Macfarlane Trust in things like the Bereavement Project. There were major differences, obviously, in that the Macfarlane registrants had no -- nothing in common to link them, except the fact that they had received infected blood and, as a result, had become HIV positive --

Q. Do you mean the Eileen Trust registrants?

A. I mean the Eileen Trust, yes. Whereas the Macfarlane Trust had -- well, two things that immediately come to mind. They would have been known to their Haemophilia

Centre, probably from birth or quite soon after. They would have had the benefit of The Haemophilia Society as a body that campaigned actively for help for them. And they would have had the benefit of being able to communicate with each other easily. That was not the case with the Eileen Trust at all.

Q. Is this fair, that given -- because the Eileen Trust was so small, and in part because of the work of Susan Daniels who knew the registrants so well, the Eileen Trust could be proactive with its registrants in a way that the Macfarlane Trust wasn't? They could suggest ways of meeting needs before the registrants even had to ask for them?

A. You don't have an example of that?

Q. Yes. We could go to EILN0000021_114. This is a letter dated 1 October 2003, and it's a letter from you. And it seems to be the Eileen Trust getting in touch with somebody on the cusp of adulthood to explain to them how services or how funding might change and suggesting different ways that need could be met. So it makes reference to the existing monthly payment and suggests making grants connected with education, computer, college books, et cetera, and then suggesting perhaps that a doctor might feel that a respite break would be appropriate, and explaining how to do that and what

could be given by the Trust. And then explaining what happens when the registrant turns 18, in terms of the regular payments. And then makes an offer about non-financial support and how that can be offered.

A. Yes. Yes. Certainly, we did do that because, yes, it was a small trust, but also because the Haemophilia Centres and their support staff, the nurses, et cetera, would have been in a position to support those registrants of the Macfarlane Trust, whereas there was no such obvious support organisation for the members of the Eileen Trust. So, yes, we were able -- we were in a position to be able to look into somebody's situation like this young man.

Q. I am going to ask you a handful of questions now about your time at The Haemophilia Society.

Can you tell us how it was that you came to be appointed as a trustee of The Haemophilia Society?

A. Well, I'd obviously known about the Society for as long as I'd been in the Macfarlane Trust. I'm not sure at what point I actually joined as a member. I worked with Karen Pappenheim over a period of some years when we were becoming more strongly aware of the number of people with haemophilia who had contracted hepatitis C but were not members of the Macfarlane Trust. And we did some work together. We knew each other. We used to

meet regularly. And at some stage when I knew that I was imminently going to leave the Macfarlane Trust, during a conversation, I simply said, "I wonder if I could join the board of The Haemophilia Society." Really, it was just putting out feelers to see -- because I obviously don't have haemophilia and none of my family do -- whether I would be a relevant applicant to become a trustee.

And Karen was enthusiastic about the idea, and I think my name was put forward, and that's how it happened.

Q. You say in your witness statement that you found The Haemophilia Society a much more sympathetic board than the Macfarlane Trust board. Can you tell us a bit about that?

A. Virtually all of The Haemophilia Society board were people with haemophilia, and they had obviously experienced all aspects of the disease and knew all about those with HIV and those who didn't have it; knew all about, from experience, what it was like to have a child diagnosed with haemophilia and there was no explanation for it, which sometimes happened; all about the stresses of being a parent and very much the stresses of being a child growing up in the era before Factor VIII when the treatment had been quite difficult

and painful and the bleeds had caused quite severe disabilities and, you know, lasting disability into life.

So they understood the registrant group -- not the registrant group, the membership group of The Haemophilia Society in a much more practical and experienced way than all the members of the Macfarlane Trust board.

Q. You said in your statement that you don't know anything about the background to the Haemophilia Society that pre-dates your trusteeship, is that right?

A. I knew that The Haemophilia Society had been founded by parents a long time before.

Q. But in terms of their policies and their thinking about various different issues, that's --

A. No, I didn't. I mean, obviously I knew that they had lobbied and eventually got the recognition which resulted in the Macfarlane Trust. I knew that we were currently lobbying about the situation of people with haemophilia who had got hepatitis C through their treatment and were now becoming very seriously ill. And I knew that they were a campaigning organisation.

Q. Do you know why the Society was campaigning for compensation for those with hepatitis C, why those with hepatitis B were excluded?

A. I don't because I don't know how widespread infection with hepatitis B resulted from treatment at all. It wasn't something that we greatly recognised.

Q. You say in your witness statement that you formed the impression that the focus of The Haemophilia Society was on young children and that because -- and that those with HIV were perceived to be provided for by the Macfarlane Trust. Can you tell us how you gained that impression?

A. Possibly through the agenda for board meetings and what we discussed as trustees. We certainly recognised that the Macfarlane Trust had been set up with a specific objective to help those with haemophilia who contracted HIV, and so it wouldn't be that there was no longer an interest in those people; it would just be that there were other priorities. And in particular at that time, it would be children and newly identified parents.

Q. When the Haemophilia Society was involved in the work around getting an Inquiry up and running, do you know whether there were any concerns expressed by the Haemophilia Society about the fact that the Archer Inquiry was a non-statutory Inquiry? Is that something you recall being discussed?

A. I don't recall it being discussed, no. I'm afraid not.

Q. Equally, do you recall any discussions about the remit

of the Archer Inquiry and whether or not that was too narrow?

A. I think we did believe it was too narrow at the time, but I think we also accepted that it was a step in the right direction.

Q. A final document from me is BART0002260. This is an information fact sheet dated September 2004 from The Haemophilia Society about vCJD. I'm not going to ask you about the contents of this, just some general questions.

This is an information fact sheet for the membership, presumably, is it?

A. Yes, it is.

Q. And are you able to tell us anything about the process that was undertaken by the Society when it published medical information for its membership at the time you were there? So, in particular, are you able to tell us how the Society went about obtaining medical information and from whom?

A. It's my recollection that we had a medical advisory panel, and that they would have advised us on all emerging aspects related to haemophilia, in particular this kind of incident where something had arisen which we felt it might be necessary to warn the members of the Society about. And you'll see that it goes on to

explain why this had a relevance to the membership of the Haemophilia Society. And I don't know whether any people with haemophilia actually contracted CJD or not. But it would have been up to our medical advisory panel to advise that this is something that, in their view, the whole membership needed to know about.

Q. Do you know whether the information and advice sought by The haemophilia Society was restricted to those on the Medical Advisory Panel?

A. No, I'm sure it wasn't. Obviously, centre directors, who could have all been on that panel, but I cannot recall, they would have very much fed information to us.

The World Federation of Haemophilia had congress every four years, at which a great deal of medical information was shared amongst the haemophilia community throughout the world.

I'm quite sure that the Society would have been very alert to all matters related to new treatments, whatever was happening in the treatment world. And, obviously, from time to time, there were new drugs introduced, and it would be up to the centre directors to let us know how -- what their value was. And if we felt it was right, we would have probably spread that knowledge.

No, it wouldn't have been limited to the Medical Advisory Panel, but that is certainly the first place we

would have referred to.

Q. Do you know what the process was, in terms of contacting the Medical Advisory Panel? Was it everybody on the Panel was contacted or particular individuals were cherry-picked because of their knowledge or for any other reason?

A. Don't know for certain, but I would imagine that Karen Pappenheim as chief executive would have been asked by trustees to contact the panel or the chair of the Panel about a particular issue and sought some more information from them.

Q. Do you know how or indeed whether the information that the Society received was checked or verified?

A. Who would you ask us to check with? Because that's why we had a Medical Advisory Panel.

Q. So the process would be, if information came in from the Medical Advisory Panel, The Haemophilia Society would accept that without further processes?

A. They would -- they might have had conversations with Centre directors, for example. But the level of standing of the Panel was such that, yes, we would have accepted the advice that they gave.

Q. One question I omitted to ask in relation to the Eileen Trust and it's this: do you recall during your time at the Eileen Trust, the Society seeking

appointment of trustees to the Eileen Trust?

A. Yes, indeed, to both trusts.

Q. Do you understand why the Society sought trustees on the board of the Eileen Trust, given that the beneficiaries or registrants from the Eileen Trust were not people with haemophilia by definition?

A. I think they felt that the Department of Health might find it easier to recruit trustees, if they would be prepared to serve on both trusts. There was not a flood of applicants when the Department sought to identify and recruit trustees for either trust.

MS SCOTT: Sir, those are my questions. Would it be convenient to take a break now so that core participants can submit any further questions they seek to ask.

SIR BRIAN LANGSTAFF: Yes, of course. What we'll do is take a break for half an hour, the -- what normally happens at this stage is that counsel checks to see what questions, if any, those who are core participants would wish to be asked on their behalf, and she'll return with further questions now at quarter to four. So quarter to four.

THE WITNESS: Can I just ask something?

SIR BRIAN LANGSTAFF: Yes, certainly.

THE WITNESS: There is an area that I would like to speak about but I didn't develop in my witness statement.

Would there be scope for this to happen?

SIR BRIAN LANGSTAFF: Yes, there will be. Our practice is that every witness, whatever their background, whoever they are, is invited at the conclusion of the questioning to say anything they wish to say, and if any questions arise out of that, they can be asked later on in writing, I have no doubt. So you must feel absolutely free to say whatever you would wish at the conclusion of the questioning.

THE WITNESS: Thank you.

SIR BRIAN LANGSTAFF: Quarter to four.

(3.18 pm)

(A short break)

(3.45 pm)

SIR BRIAN LANGSTAFF: Yes, Ms Scott?

MS SCOTT: Can you see and hear me?

A. Yes, I can.

Q. I've got a handful of questions to ask you from the core participants so they'll dot about a bit.

A. Yes.

Q. So we looked at earlier at the Payments Review Group's recommendation on the cost of living with HIV and haemophilia in 1999. Was one done for the cost of living with HIV for infected partners, ie people that didn't have haemophilia?

A. Not to the best of my knowledge, no.
Q. Do you know why not?
A. I don't, no.
Q. We looked earlier at some of the different types of loans that Macfarlane Trust entered into with its registrants. We looked at the loans by exchange of letters. Do you know or can you recall whether or not the registrants entering into those loans were advised to get legal advice?
A. I can't recall but I think it unlikely.
Q. The same question for those registrants entering into loans security by legal charge. Were they advised to get independent legal advice?
A. Again, not to my knowledge. In no way would they have been discouraged from doing so and common sense would suggest that perhaps they should have.
SIR BRIAN LANGSTAFF: I suppose to ask someone who is seeking a loan or an equity agreement on their house because they are short of money, to ask them to obtain independent legal advice might be to ask them to incur an expense at lawyers' rates.

Presumably, the only way in which that could be achieved reasonably would be for the Trust to fund the advice, would it not?
A. That is certainly one way and it's not something that we

would have refused funding for. They could also have gone to the Citizens' Advice Bureau or to any free legal service that was available to them locally.
SIR BRIAN LANGSTAFF: Yes, thank you.
MS SCOTT: Do you have any recollection of funding such legal advice for anybody that entered into a loan?
A. No, I don't.
Q. We looked at the Macfarlane Trust handbook which set out the details of the regular payment scheme and the single payment scheme and provided information about procedures and how to make applications and what evidence would be required. Is it right that the Eileen Trust did not have a similar publication?
A. I don't think they did. I think it is much more likely that by personal interview, either with a social worker, possibly with me, possibly with the benefits adviser, they would have been advised on the rates, as soon as a need had been flagged up. It's a much more personal one-to-one relationship.
Q. So is the answer to the question "Why didn't they have a handbook?" is the answer to that because they didn't need one because of the personal interaction?
A. Yes.
Q. During your time at the Macfarlane Trust, do you recall whether widows were means tested to establish their

eligibility for grants or payments?
A. Not if they were already eligible for those grants and payments.
Q. So those categories that we looked at, the incapacitated widow, the widow with children, would not have been means tested for those, the £100 per month that they got after the -- six months after bereavement?
A. No, no.
Q. You were explaining in your evidence earlier that the more proactive approach of the Eileen Trust, in terms of offering support, anticipating the needs of its registrants, and the reason that you gave for that or one of the reasons you gave for that was the fact that the registrants had less support than the registrants at the Macfarlane Trust because they weren't associated with Haemophilia Centres, and so on. What, if any, consideration was given to the support requirements for Macfarlane Trust registrants who were not attached to Haemophilia Centres, for example infected partners or indeed widows and dependants, or a person with haemophilia attached to a centre who didn't have a social worker or nurse who could assist with grant applications?

So the question is, what consideration was given to the support requirements of those registrants by

Macfarlane to anticipate and assist them with obtaining appropriate funding from the Trust?
A. Obviously we set up a number of groups which would have brought together those particular categories. We had opportunities for widows to meet, opportunities for infected intimates to meet, and we also, as far as I know, would have made it quite clear to an infected intimate, widow that she would receive the same information as anyone, any other registrant of the Trust after her husband's death.

You refer to people with haemophilia and HIV who were not attached to a Haemophilia Centre. If they were registered with the Trust they would have received all the information that the Trust sent out to all its registrants.

It wasn't just made available to them through the Haemophilia Centres; it was made available to them as individuals. If they missed out on information about -- I cannot really think, but perhaps a particular new service they should have heard about, I would like an opportunity to perhaps know what that might be. But we certainly circulated all our registrants with the information, regardless of whether or not they were attached to a Haemophilia Centre and had a social worker.

The Trust social worker would have helped such people to apply for funding from the Trust.

Q. This morning, at the beginning of your evidence, you were giving evidence about the perception within Macfarlane Trust that the Trust may have a 2012 cutoff and in that evidence, you said that the perception was that the Trust would continue for the natural life of the registrants. Did you mean by that the primary beneficiaries, people with haemophilia, with HIV?

A. Yes, yes. I think I did.

Q. What consideration do you understand was given by the trustees to the fact that, even assuming that all of the people with haemophilia and HIV would have died within a certain period of time, given the life expectancy when the Macfarlane Trust first came into being, what about the natural life of the dependants?

A. I'm only able to speak of what I was advised when I joined the Trust, which was that it had been set up as a trust that was not expected to last more than a certain number of years, with an expectation that there would be no living registrants at the end of that time. I do not know whether, and I was never told whether, there was any expectation of there being dependants of the Trust who would require support for longer. I'm not sure that it had been addressed in

those early days at all.

SIR BRIAN LANGSTAFF: One of the things which I'm going to have to consider when I come to the stage of reporting is the terms upon which the Trust was granted. You might like just to have a look at this as a matter of interest, and it's MACF0000003_064.

Can we go to paragraph or clause 4 of the trust deed, please, Soumik.

Try page 3 or 4, next page. If we look at clause 4, I don't know if you ever had your attention drawn specifically to this, but this is the trust deed and this is the part which sets out what the Trust is for. It says to me, admittedly I'm taking a lawyer's approach to this:

"The objects for which the Trust is established are to relieve those persons suffering from haemophilia who as a result of receiving infected blood products in the United Kingdom are suffering from Acquired Immune Deficiency Syndrome or are infected with [HIV] and who are in need of assistance, or [and this is the bit] the needy spouses parents children and other dependants of such persons [ie of people who have been infected with HIV through blood products] and the needy spouses, parents, children or other dependants of such persons who have died."

Anyone who had had regard to that, I would have thought, in drafting it, must have had in mind that if someone in their early middle age died leaving children and dependants, that might go on for very much longer than the period of time that you're telling us about, but that view was not reflected in anything you heard, from what you're telling us.

A. No, I don't think it was, no. I think my understanding, which may have been deficient, was that the Trust as such was not expected to be a long-lived trust. That could have just been the opinion of the people who spoke to me at the time but that is what they told me at the beginning.

SIR BRIAN LANGSTAFF: Presumably, that view was something which affected the way in which the Trust conducted itself and thought it should conduct itself?

A. Well, at the time I joined, it was just after combination therapies were produced, proving very successful, and it was becoming clear that the lifespan of the primary beneficiaries was likely to be uncertain, but longer than had been expected, when the Trust was set up.

SIR BRIAN LANGSTAFF: Yes, thank you very much.

MS SCOTT: Did the Macfarlane Trust consider it to be within its remit to provide funds for the needs of its

registrants which arose from hepatitis C as well as HIV?

A. As I think it stated in the paperwork provided, the Trust regarded a registrant of the Trust as being the whole person and that any other accompanying physical illness or disability was included in their response to the needs of that person.

Q. You said in your evidence earlier this afternoon that applications for special payments required support from social workers or OTs or other medical professionals who would identify the need for that single payment.

A. Yes, it is a single -- it's not a special payment, it's a single payment.

Q. Single payment, yes, sorry.

A. Yes.

Q. Given that this required registrants to approach the very medical professionals at the very centre where they had been infected with HIV, did the Macfarlane Trust give any consideration to that fact, that in effect, it made those who were responsible for the infections the gatekeepers to the single payments, and that that may act as a deterrent to applications being made?

A. I don't think it ever occurred to us that we would ask for independent medical information about one of the registrants. Whether or not the registrants felt deterred from asking for grants from the Trust because

there would be medical information sought from the Centre which would be responsible for the treatment which had led to their infection, I don't know.

Q. Were any efforts made to ensure representation on the Partnership Group or amongst user trustees from the devolved nations, so for Scotland, Wales, Northern Ireland?

A. I don't believe so. Not necessarily, no. In Scotland, The Haemophilia Society was a completely separate charity under different charity rules. In Wales, I don't think at that point it was a devolved country, and in Northern Ireland, certainly in my role, I regarded Northern Ireland as part of the area that we were responsible for, as I did with Wales, whether or not the Trustee Board felt the necessity to have representation from each of those countries, I am unaware.

Q. When you were having meetings with the Government, if I can put it like that, were they meetings simply with the Department of Health, or did you have -- do you recall having any meetings or any interactions with the Scottish executive after 1999?

A. The only occasion I ever recall meeting anyone from the Scottish executive would have been when I was a Haemophilia Society trustee and went up to visit. So

no.

Q. I asked you about emails referring -- that passed between Peter Stevens and Gordon Clarke earlier. Another phrase that emerged from emails between trustees was "whingeing haemos". Do you recall hearing or seeing, in written communications, anybody using that phase?

A. No, I don't, and if I had, I should have recorded it as something that I felt was totally wrong and inappropriate.

Q. Do you recall attending any meetings to discuss the use of derogatory or disparaging terminology used about registrants and the beneficiary community?

A. No, I don't.

Q. And do you recall hearing of, or witnessing firsthand, trustees or staff members referring to members of the beneficiary community in derogatory terms?

A. No. No, I don't.

MS SCOTT: Those were all of the questions, sir.

Questions by SIR BRIAN LANGSTAFF

SIR BRIAN LANGSTAFF: Thank you.

Not long ago in this Inquiry -- well, let me begin, actually, in this way: you've spent most of your life, have you, in -- your working life, that is -- in the charitable sector?

A. Yes.

SIR BRIAN LANGSTAFF: And before you worked for the Macfarlane Trust and the Eileen Trust, from what you've said earlier, you were working, I think, essentially with charities which provided services.

A. Yes.

SIR BRIAN LANGSTAFF: The difference between those sorts of charities, and indeed The Haemophilia Society itself, is that the principal role of the Macfarlane Trust, back to the Eileen Trust, was as a grant-making charity; am I right?

A. Yes.

SIR BRIAN LANGSTAFF: So was that a new experience for you?

A. No. We had given grants when I was at -- through the Blue Peter fund, in fact, when I was at what was then The Spastics Society. We had certainly fundraised and sought grants when I was at St Christopher's Fellowship. So that -- no, it was not an entirely new experience, but what was new was the source of funding was from one source only and that the community, the beneficiary community, was very specific.

SIR BRIAN LANGSTAFF: We heard a view expressed not long ago in this Inquiry that if one had a list, a tariff list, if you like, of so much for such-and-such a piece of equipment, just as in the office guidelines, and if it

were published to those who were registrants or beneficiaries that, inevitably, people being people, so the view went, that they would seek the -- something which was of the maximum value to the top of the range for which allowance was being made.

Would that have been your view of this particular community?

A. No, definitely not. First of all, the recommendations for grants came after careful assessment either by the Trust's social worker, or a social worker at a centre, or even a local authority social worker who would assess the need. There wouldn't be a question of people necessarily just wanting the most expensive thing on the list. I don't regard anyone ever regarding that simply as a shopping list.

SIR BRIAN LANGSTAFF: Did you ever see any reason to distrust, in the main at any rate, the applications made to the charity for a grant?

A. No.

SIR BRIAN LANGSTAFF: You took the job, I imagine, at Macfarlane because you hoped that you would find fulfilment, personal fulfilment, in occupying that role in that charity for a period of time; am I right?

A. You are right, yes.

SIR BRIAN LANGSTAFF: Did you?

A. Yes. Very much so.
SIR BRIAN LANGSTAFF: Is that why you then -- or why, at about that time, you then went on to become a trustee, voluntarily, unpaid --
A. Yes.
SIR BRIAN LANGSTAFF: -- of The Haemophilia Society itself?
A. Yes.
SIR BRIAN LANGSTAFF: As a matter of interest, had you known Karen Pappenheim from her work in charities prior to your taking up the role with the Macfarlane Trust?
A. No, I hadn't. No.
SIR BRIAN LANGSTAFF: The difference between The Haemophilia Society and its charitable activities and that of the Macfarlane Trust may perhaps have been that The Haemophilia Society felt free to -- indeed, it felt it partly its job to campaign for better treatment by Government of those who had suffered from infected blood products, as well as campaigning in other respects for the general benefit of those who had the condition of haemophilia.
That campaigning aspect was broadly absent, was it, from the Macfarlane Trust?
A. It was entirely absent. I was certainly told on my very first interview with the trustees that this was a campaigning body, that the fund -- we were

administering the fund on behalf of Government, and that no liability had ever been admitted by Government, and our role was very specifically to administer the funds for the benefit of the beneficiary group.
SIR BRIAN LANGSTAFF: Had that approach, the approach of the campaigning for the beneficiary group, been an approach which some of your earlier charities had taken on behalf of their particular communities?
A. What, not to campaign?
SIR BRIAN LANGSTAFF: No, to campaign.
A. To campaign? Yes, the previous charities certainly were campaigning. I mean, we had a campaigns department at The Spastics Society, which is now Scope. And we regularly campaigned on the part of homeless young people when I was at St Christopher's. So, yes, campaigning was part of my previous existence.
SIR BRIAN LANGSTAFF: So a further distinction perhaps between the Macfarlane Trust as a charity and the other charities with which you had association, both before and after your work for Macfarlane, was that they did not feel at all constrained in campaigning on behalf of those whom they served?
A. Yes.
SIR BRIAN LANGSTAFF: Yes. Thank you very much.
MS SCOTT: Sir, I've just got two further questions that

have been handed to me, if I may.
SIR BRIAN LANGSTAFF: You won't mind? Please go ahead.
MS SCOTT: The first one is in relation to the childless widow, so the childless widow, the cohort of widows whose support stops after 15 months.
Was there any scope for such a widow who subsequently becomes unwell to apply back to the Macfarlane Trust to receive support? So she becomes an incapacitated widow after having her support stopped. Was there any scope for her to apply back in those circumstances?
A. She could certainly have applied back. Whether or not she would have been recognised as an incapacitated widow who would need continuing support would have been an individual judgment of the Trustee Board at that time.
Q. And are you aware of any steps taken to ensure that widows were aware that they could do so?
A. No. Apart from keeping in touch with them and through the Bereavement Project, in particular, we probably would not have known. If they wanted to remain in touch with the Macfarlane Trust, they probably could have done so. But I'm not quite sure what would have been the main avenue for them to keep connected, as it were.
Q. So there wasn't a route that springs to mind --
A. No.

Q. -- for them to keep in touch.
Was the -- we spoke about the Macfarlane Trust handbook, and you, in your evidence, said that it was sent out every year to the registrants. Was it also sent to widows?
A. Certainly, if they were infected intimates. I'm not aware of whether we sent it out to all the widows. At this distance of time, I can't recall.
MS SCOTT: Those are the questions. Thank you.
SIR BRIAN LANGSTAFF: Thank you very much. Now, is there anything that you would like to say? Feel free.
A. Yes.
SIR BRIAN LANGSTAFF: You can take as long as you like.
A. It's a particular area over which I felt concern when I was working at the Trust and have felt continuing concern, and it is one that I don't believe was addressed, as far as I know, by trustees in my time, and I don't know subsequently. It is to do with the area of life insurance.
Now, I mean, as you will be aware, anyone who is infected with HIV has, since the inception of the recognition of HIV, has been unable to get life insurance. What I think we failed to recognise was that for almost all mortgages, life insurance is a requirement. Now, I know that Susan Daniels was able

to obtain mortgages for people with HIV and haemophilia through connections, and I know that, at the time -- certainly when I was there, possibly previously -- the issue of life insurance was never really addressed. But in most people's situation, when they are a couple and one of them dies, the life insurance that has been attached to the mortgage would be payable to release the partner from the incumbency of the mortgage.

I don't believe that Government ever recognised the difference for people who had been infected with HIV through their treatment, and what a major difference this would make in the lives of their widows and partners. I believe it is an area that should be addressed. And if one looks at the differences between those people living with HIV and haemophilia, or indeed not but just with HIV, that they have received through their treatment, I believe that it's never been recognised that one of the major ways in which their life was changed forever was the lack of life insurance.

And I believe that there is scope to recommend that this situation be examined and that the possibility of recognising what would have been available to widows at the death of their partner, had there been life insurance in place, should be recognised as something which could actually be back-paid, if you like. I think

that's particularly important where people have been living with the results of having had a charge or an equity loan or something else on their property for many years. And, obviously, I'm talking in particular about one lady, but not only. I believe that the whole issue of life insurance was not looked at by the trustees, by Government, to the best of my knowledge, and that the deficit in the lives of people was not recognised because it wasn't looked at. Some questions are too difficult to look at.

SIR BRIAN LANGSTAFF: Thank you.

I want to thank you very much for being prepared to give us your evidence and your insight and give us another view of the way in which the Macfarlane Trust operated, albeit a period, in your case, of some seven years, from 1997 to 2003.

I think, to me, if I may say so, what encapsulated a lot of your approach is summed up in a phrase which you used about the user or registrant trustees, which was that they might be more clearly -- give a more clearly understanding view of the needs of beneficiaries. And I think that's just an example of what seemed to me to be evidence full of gentle and kind difference rather than criticism from the -- of the views of others.

Well, I've heard what might be said to be the underlying criticism, and I've noted it. I've noted, in particular, the courteous way in which you've expressed it. And I want to thank you for all that and for the insight which you've given us.

That is where we finish for tonight. I just have to tell -- or ask Ms Scott -- I think I already know -- what we're doing tomorrow, but it's your role to tell everyone, Ms Scott.

MS SCOTT: Yes. Tomorrow, ten o'clock, Christopher FitzGerald is coming to give evidence.

SIR BRIAN LANGSTAFF: So ten o'clock tomorrow. Until then. Thank you very much.

THE WITNESS: Thank you.

(4.20 pm)

(The hearing adjourned until 10.00 am the following day)

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