

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?

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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

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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

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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

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

3 **A.** That's right.

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

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

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

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

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

16 **A.** Yes.

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

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

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

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

12 **A.** That's my recollection, yes.

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

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

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

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

10 **A.** That's right, yes.

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

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

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

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

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1 knowledge of managing money.

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

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

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

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

4 **Q.** Was your approach different?

5 **A.** Yes, I think it was.

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

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

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

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

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

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1 the benefit of all the registrants.

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

5 **A.** No.

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

7 **A.** I joined in '97. I would have said by '99, certainly
8 1998/99, it was becoming more of a feature, recognised
9 in The Haemophilia Society and in the Macfarlane Trust.

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

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

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

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

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

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

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

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

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

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

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

8 **A.** Do you mean --

9 **Q.** The 2012 --

10 **A.** You mean the increasing --

11 **Q.** The 2012 cut-off date.

12 **A.** When -- after the strategic review, that's the first of
13 our reviews, I think by then we did realise that there
14 was a likely termination date, and I understood that to
15 be 2012. And at that stage, it became clear that after
16 1997, when the introduction of combination therapies had
17 occurred, that the life expectancy of the registrants
18 was very uncertain but likely to be longer and not --
19 and that it was no longer a terminal illness.

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

22 **Q.** So is it right to understand the information about the
23 2012 cut-off date was information that was -- that came
24 from within the Macfarlane Trust itself, rather than
25 from the Department of Health, for example?

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

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

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1 MACF0000005_041. This is one document -- the Inquiry
 2 has received this document in this form. It's not these
 3 minutes I want to take you to, but just to talk you
 4 through the documents.
 5 So there's trustee minutes from 10 February 1998,
 6 and then if we go through to page 7 of the document,
 7 which is the first document that comes after the trustee
 8 minutes, there's an administrator's report which goes
 9 over to page 8. And then the document I want to take
 10 you to is page 9, and you will see there that it's
 11 a document entitled "Statistics summary at
 12 30 April 1998". I'm unclear why that's part of the same
 13 document from the February '98 minutes -- meeting
 14 minutes, but there we go.
 15 Just before we look at the detail on this document,
 16 were these documents generated by you or by your staff
 17 for board meetings?
 18 A. These would have been prepared by the staff team. By
 19 April 1998, I believe we had a finance officer in
 20 post -- in fact, I'm virtually certain we did -- and it
 21 would have been his responsibility to prepare these in
 22 discussion with the staff.
 23 Q. And they would have been provided to trustees for board
 24 meetings, would they?
 25 A. Probably not every board meeting. Certainly regularly

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

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

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

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

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

16 Q. Certainly we've got, during your tenure, one from '98,
17 '99, 2000. I don't think we've got 2001 and 2002.
18 Could that be because there wasn't one in 2001 and 2002?

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

20 Q. Soumik, can we go to page 19 of that document? We'll
21 look at various different parts of this document, but
22 I just want to start at page 19. So that's where it
23 sets out who the trustees were, and over the page at
24 page 20, it sets out the staff team.
25 So we can see a picture of you and 1997, which

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1 other bodies on your behalf."
2 We can also see there Carol. I understand that's
3 Carol Clisby; is that correct?

4 A. Yes, that's correct.

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

7 A. Yes, I think, yes.

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

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

11 Q. And we see there that:
12 "She deals with queries about Social Security
13 benefits, can sort out problems with the DWP, and help
14 with appeals against unsatisfactory decisions, and help
15 attend appeal hearings if necessary."
16 She also -- if we turn over the page to page 22,
17 there's some pages entitled "Welfare benefits". Would
18 Carol Clisby have been responsible for drafting these --
19 this sort of information for the handbook and indeed for
20 newsletters and so on?

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

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

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1 indicates you started in 1997. And we can see there
2 that Claudette Allen was the social worker, and she --
3 is it right to understand she would have started in
4 2000?

5 A. That's right, yes.

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

7 A. Yes, she did.

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

10 A. Yes, that's right.

11 Q. And we can see --

12 A. *(inaudible)*

13 Q. Sorry?

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

16 Q. Mr Tudor Williams?

17 A. Yes, that's right.

18 Q. We see Claudette sets out what her role was at the
19 Trust:
20 "Claudette is our social worker and is responsible
21 for all types of help and advice to registrants. She
22 can answer queries about Trust payments and provide
23 advice and help about most aspects of living with HIV.
24 [She] is in regular contact with Haemophilia Centres and
25 The Society, and she can contact local authorities and

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1 Q. Roz Riley, administrative secretary --
2 A. Yes.
3 Q. -- and Lisa -- I'm afraid I don't know Lisa's second
4 name -- finance assistant. So that was the staff team
5 in 2003.
6 A. Yes, it was.
7 Q. And the size of the team, it was broadly consistent, was
8 it, during your tenure?
9 A. When I first arrived, there was Jenny Jackson as
10 benefits advisor. There was Peter Williams, a social
11 worker. There was Funmi Hassan, who did all the
12 administrative work, and there was John Williams.
13 Pretty soon after I joined, I felt we needed more
14 robust financial support in the office, and the deputy
15 chairman agreed, and so the finance officer post was
16 created.
17 Q. And in addition to these staff, so employees, is it
18 right that Susan Daniels was also providing independent
19 financial advice to registrants, or financial advice to
20 registrants?
21 A. Yes. I'm not quite sure when that arose. Susan --
22 Susan was available to registrants about the time that I
23 joined, and maybe for longer. I'm not sure when her
24 help was introduced, but it was certainly -- at that
25 first stage, she ran her own private business, providing

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- 1 advice. Later, she joined a company, providing advice
2 on financial matters and investment.
- 3 **Q.** And Susan Daniels is due to give evidence to the
4 Inquiry, so we can no doubt ask her those questions.
- 5 **A.** No doubt.
- 6 **Q.** Soumik can we go to page 7, please, of this document --
7 page 8 of this document. So here we've got the section
8 "Financial help from the Trust", and this is the section
9 that sets out the different payments that can be
10 obtained from the Trust. So if we go over onto the
11 following page, we can see here the regular payments,
12 winter payments, and then if we go over the page, single
13 payments. So were those the three types of payments
14 made by the trust during your time there?
- 15 **A.** Yes, they were. The additions, obviously, were related
16 to housing and debt, which would have depended on
17 Susan's recommendations to us, and quite a lot to do
18 with loans and equity loans, et cetera, but I'm sure
19 we'll come on to that later.
- 20 **Q.** We'll come on to that, but the payments or the grants or
21 the payments that would have been made to registrants to
22 discharge debt, or in relation to housing, leaving to
23 one side the equity share loans, would either have been
24 single payments, would they, or potentially loans?
- 25 **A.** Yes, yes.

21

- 1 payment at some rate, just ask."
- 2 Is it right to understand that, talking there about
3 those that are registered, meaning what we sometimes see
4 referred to as "primary beneficiaries" --
- 5 **A.** Yes.
- 6 **Q.** -- ie those people with haemophilia infected with HIV?
- 7 **A.** Yes. Regular payment also paid to widows, and for -- to
8 infected intimates at different rates.
- 9 **Q.** Yes, we'll come on and look at that.
- 10 **A.** Yes.
- 11 **Q.** It says there "just ask". So is it also right to
12 understand that, in order to get a regular payment, you
13 needed to make an application for one?
- 14 **A.** No, because at the outset of the Trust, regular payments
15 word part of the package of benefits to the registrants
16 and we had a complete list of registrants.
- 17 Later, there would have been circumstances which
18 changed, for example, when infected intimates -- when we
19 became aware of infected intimates or indeed of children
20 born with HIV, so there would have been increases.
21 Those would have been advised to us mainly by the
22 Haemophilia Centres. They would have advised that there
23 was someone else who should rightly expect to receive
24 a regular payment.
- 25 **Q.** So was it the case during your time there that everybody

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- 1 **Q.** There wasn't a category of grant in its own right?
- 2 **A.** It wouldn't have fallen within the grant, the normal
3 grant guidelines.
- 4 **Q.** I understand.
- 5 **A.** These were discretionary payments and, depending on
6 their size and their need, it could have been a direct
7 grant. More often, it related to housing debt. It
8 probably would have been some kind of loan, either
9 secured by charge on the house or an equity loan
10 agreement, which I think is something that had been
11 started fairly early on in the life of the Trust.
- 12 **Q.** We'll certainly come back both to the issues you raised
13 there, the discretionary payments outside the guidelines
14 and the loans.
- 15 **A.** Yes.
- 16 **Q.** So if I can start, then, on looking at regular payments.
17 Soumik, can we go back to the page before? So we look
18 at regular payments, and it sets out there the
19 substantial increase in regular payment from
20 September 2000, and I'll ask you some questions about
21 that in due course, and then saying that there's
22 a further review that is going to be taken, unlikely to
23 lead to major revisions:
24 "Who can have a regular payment?"
25 "Everyone registered is eligible for a monthly

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- 1 who was registered with the Macfarlane Trust received
2 a regular payment?
- 3 **A.** Yes, I can't think of anybody who didn't and any reason
4 why they shouldn't have.
- 5 **SIR BRIAN LANGSTAFF:** May I just ask, suppose the case of
6 somebody who has HIV, who is a primary beneficiary, to
7 use those terms, they have a family, they die. Because
8 they had HIV and because of the care given to them by
9 members of their family, the family suffers from greater
10 hardship than they would have had if he had not had HIV,
11 but he is no longer a registrant because he's dead.
- 12 **A.** Yes.
- 13 **SIR BRIAN LANGSTAFF:** Potentially, you have a number of
14 further registrants, do you, because they are within the
15 terms of the original trust deed; they are dependents
16 and widows, or spouses or partners.
- 17 **A.** There would have been payment to widow.
- 18 **SIR BRIAN LANGSTAFF:** But not to the children? What if the
19 person who dies is a single parent?
- 20 **A.** Sorry, you'll have to expand on that. You mean if there
21 was -- most of the people who died at that stage were
22 men, fathers.
- 23 **SIR BRIAN LANGSTAFF:** Yes, but they may have been
24 responsible for children, their wife may have died --
25 assuming they'd been married, their wife may have died

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

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

9 **SIR BRIAN LANGSTAFF:** Yes.

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

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

17 **A.** I think the payment would have -- if they were infected,
18 and some of them were, then they would have their own
19 payment, yes. If they were not infected but dependent
20 on the father, as his dependant, then they would
21 continue to be supported by the Trust until they were
22 18, and if they went on to further education, they would
23 be supported through that period of further education.

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

25

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

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

12 **A.** Certainly not during my tenure.

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

15 **A.** Yes.

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

17 **A.** Yes, I see. Yes, okay.

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

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

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

25 **A.** Exactly.

27

1 **A.** It did, yes.

2 **SIR BRIAN LANGSTAFF:** Thank you.

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

5 **A.** Yes.

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

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

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

13 **A.** Yes.

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

21 **A.** Yes.

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

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

26

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

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

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

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

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

29

- 1 The second is, and possibly related to it, there
- 2 simply wasn't enough money to give both the same rate
- 3 and so a hard decision will have to be made and it was
- 4 to give the partner a lower rate. Are you able to
- 5 assist --
- 6 I'm not sure that's a choice, actually, because the
- 7 second is also a policy decision, isn't it?
- 8 **MS SCOTT:** Yes.
- 9 **SIR BRIAN LANGSTAFF:** So your first question, is it a policy
- 10 decision or is it something else, actually, you've
- 11 answered it.
- 12 **MS SCOTT:** Yes.
- 13 **A.** Certainly, during my tenure, there was never a policy
- 14 decision to pay less money to infected intimates or
- 15 children. It is my understanding that the situation
- 16 developed over time and that the trustees -- before
- 17 I joined, certainly -- that the trustees would have come
- 18 to a decision that regular payments should be paid to
- 19 anyone who was infected with HIV through blood products
- 20 or through intimate relations with someone who was
- 21 infected.
- 22 At some point in time before I joined, there must
- 23 have been a decision about how much should be paid.
- 24 Now, I have no knowledge of how that decision was to
- 25 come about, or whether it was a policy decision as such.

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

30

- 1 I don't think, in my tenure, that there would have
- 2 been a question of one person being more deserving than
- 3 another. I think they would have referred back to the
- 4 trust deed which was about people with haemophilia who
- 5 had been treated with infected blood.
- 6 I also don't think that there would have been any
- 7 question of such a decision being influenced by
- 8 perceived lack of money. Obviously, it would have been
- 9 a situation which had to be considered early in the life
- 10 of the Trust, and I have no knowledge of how that
- 11 decision was reached. But I don't think we should
- 12 assume that it was dependent on a view that one person
- 13 was more important than the other.
- 14 **Q.** If that was a policy decision, would that be wrong, in
- 15 your view?
- 16 **SIR BRIAN LANGSTAFF:** I think that's really a question
- 17 ultimately for me, isn't it? One can see that the
- 18 scheme was not a scheme to compensate those who had got
- 19 HIV. They had to have it through infected blood
- 20 products, and that was the original scheme.
- 21 **A.** Yes.
- 22 **SIR BRIAN LANGSTAFF:** So it's those who were suffering from
- 23 HIV as a result of having infected blood products, or
- 24 the needy spouses, parents, children, other dependents
- 25 of such persons. So it was envisaged, as I read the

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

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

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

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

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

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1 **Q.** -- if they had certain --

2 **A.** That was related to mobility, yes.

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

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

8 **A.** Yes.

9 **Q.** -- no matter what the circumstances were?

10 **A.** That's my recollection.

11 **Q.** It's your recollection?

12 **A.** They were also paid a bereavement grant.

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

18 **A.** No, I don't.

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

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

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

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1 same or not.

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

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

7 **Q.** So to be --

8 **A.** That's my recollection.

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

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

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

25 **A.** Yes.

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1 **A.** Yes.

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

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

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

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

23 **A.** That is correct.

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

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

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

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

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

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

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

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

7 (11.15 am)

8 (A short break)

9 (11.45am)

10 **SIR BRIAN LANGSTAFF:** Yes, Ms Scott?11 **MS SCOTT:** Ms Hithersay, can you see and hear me?12 **A.** I can, yes. Can you see and hear me?

13 **Q.** I can. Can I just ask you to clarify one of the answers
 14 you were giving just before the break. The sound wasn't
 15 terribly good, and I just want to check the answer.
 16 I had asked you whether you agreed with the evidence
 17 from Mr Stevens that the Macfarlane Trust was
 18 inadequately funded by the Department of Health. I am
 19 just going to read you the transcript of what you said,
 20 and just check with you to see if what you said was what
 21 you meant, or --

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

25 That was the question.

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1 inadequately funded by the Department of Health?
 2 **A.** That is a very difficult area because I found during my
 3 tenure that each time we went to the Trust with
 4 recommendations for higher payments, due to changing
 5 needs, that was not refused. So it would not be right
 6 to say that that was purely due to inadequate funding
 7 from the Department of Health. It would be also
 8 accurate to say that we did not highlight that
 9 particular area of need to them and ask for
 10 substantially more money to support the widows without
 11 dependants and -- well, indeed the -- all the widows,
 12 except those who were infected with HIV. They all could
 13 have had greater support and didn't, and that was partly
 14 our lack of bringing that to the notice of the
 15 Department of Health.

16 **MS SCOTT:** Sir, I note the time. I have a few more
 17 questions on the regular payments and questions on the
 18 other payments, but I can pick that up after the break.

19 **SIR BRIAN LANGSTAFF:** Well, if it's convenient now, then
 20 we'll take a break.

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

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1 Your answer was:

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

6 Did you mean --

7 **SIR BRIAN LANGSTAFF:** It was the Department, not the Trust.

8 **A.** Yes, yes. I meant the Department of Health.

9 **MS SCOTT:** You meant the Department of Health, thank you.

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

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

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

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

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

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- 1 orphans as set out here?
- 2 **A.** Certainly, if the orphans were dependants of the primary
3 beneficiary, they would continue to be supported as
4 dependants of the Trust until they reached the age of
5 18.
- 6 **Q.** Would you accept that that's not set out here as part of
7 this scheme here. That is not clear on --
- 8 **A.** It's not clear. It says a transition payment is also
9 available for those caring for orphans. Yes, it doesn't
10 spell it out. It should spell it out more clearly.
- 11 **Q.** So that seems to be the extent of the payment for
12 orphans set out here. I think we can agree that; is
13 that right?
- 14 **A.** It says:
15 "Guardians [or] carers of orphans will be paid the
16 same rate as widowed mothers."
17 That would continue for as long as those children
18 were dependants.
- 19 **Q.** Where does it say that?
- 20 **SIR BRIAN LANGSTAFF:** Footnote 2.
- 21 **MS SCOTT:** Sorry, footnote 2.
22 So here, under this policy, guardians or orphans are
23 paid same rate as widowed mothers?
- 24 **A.** Yes.
- 25 **Q.** So the ongoing payments for orphans will be equivalent

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

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

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

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1 children in those circumstances, from the Trust?

2 **A.** I'm not sure how it was set out in any guidance but

3 certainly during my tenure one or two families came to

4 light where the mother had subsequently moved away with

5 the children and it took us a while to realise that

6 there were dependant children. It was not a deliberate

7 decision to exclude children from being dependants of

8 the Trust because the parents had got divorced.

9 **Q.** So, as far as you're concerned, is it right to put it

10 like this: that children in those circumstances should

11 have received regular payments from the Trust until they

12 were either 18 or longer if they were in full time

13 education?

14 **A.** That is right, and where children were identified in

15 that category, back payments would have been made and

16 they would have become established dependants of the

17 Trust.

18 **Q.** Can you recall any situations where, given that those

19 payments were at the discretion of the trustees, that

20 discretion was exercised against making payments to

21 children in those circumstances?

22 **A.** No. No, definitely not.

23 **Q.** Can we look briefly, then, at how these rates were set.

24 Soumik, can we have MACF0000007_137. This is

25 a document "Payments Review Group -- Briefing", dated

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1 to see the best way to address this. We probably would

2 have discussed it at a staff meeting. We would have

3 wanted to involve registrants themselves. I cannot, at

4 this stage, recall exactly how the Payments Review Group

5 operated but we certainly would have included discussion

6 with the registrants. We would have included, as is

7 obvious from the membership, those who were working

8 directly with people with haemophilia in the centres.

9 And through the staff team, we would have been talking

10 to both the benefits adviser and the social worker in

11 particular.

12 We might -- particularly if there were issues

13 related with housing which needed to be drawn into the

14 discussion, we would have involved Susan Daniels.

15 **Q.** And it says there, third paragraph down:

16 "The group used the original 1993 paper produced by

17 the Trust at the time of the last major review of

18 Regular Payments, adding to those where new issues were

19 raised and updating costs related to the areas

20 originally identified."

21 Then the group goes on to set out the major changes

22 as experienced since 1993. The first one:

23 "The majority of those living today are unemployed,

24 whereas in 1993, many of those who were well were still

25 in employment. In most cases where men had been in

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1 December 1999. I think you refer to this in your

2 witness statement and you explain that the Payments

3 Review Group was a group in which Mark Winter and the

4 social workers formed a part; is that right?

5 **A.** Yes, that is.

6 **Q.** We can see there that it's a briefing on the cost of

7 living with haemophilia HIV and combination therapies,

8 and it says --

9 **A.** Yes.

10 **Q.** -- at the top there:

11 "A group of registrants and ... staff met together

12 to reassess the cost of living with haemophilia, HIV

13 virus and combination therapies."

14 It goes on to say:

15 "The group considered their way of life, and ways in

16 which the daily cost of living was increased by living

17 with symptoms ... of haemophilia, HIV and hepatitis C

18 related illnesses. [It] compared expenditure in a range

19 of areas, and attempted to determine how this differed

20 and was greater than similar expenditure ... for [an]

21 average family."

22 Were you part of that group, do you recall? Do you

23 remember doing any work in relation to this aspect of

24 the group's work?

25 **A.** Not personally. I do recall drawing together the staff

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1 permanent relationships, partners were also in

2 employment. Today, many relationships have broken down

3 due to the burden of caring and of living with a partner

4 who was HIV positive. Many partners today were

5 unemployed and engaged in caring for their partner and

6 sometimes their children."

7 Then secondly:

8 "In 1993, all registrants had received two tranches

9 of capital payment from Government. They were able to

10 afford to by household goods, go on holiday, and afford

11 some luxuries. Today, well over 70 per cent of Trust

12 registrants are largely dependent on state benefits and

13 Trust funding. This meant that the majority of people

14 registered with the Trust are living at or below the

15 poverty line. This is more than twice the national

16 average."

17 Thirdly:

18 "In 1993, there was no successful treatment for

19 AIDS. People either got ill and died, or remained

20 asymptomatic and continued their daily life watching

21 many of their friends die and living with a very short

22 life expectancy and no hope. Today, combination

23 therapies means that for many there is a hope of

24 a future, albeit uncertain. Many people will be sick

25 for much of the time, living with chronic illness and

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

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

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

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

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

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

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

6 And then towards the bottom of that page:

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

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

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

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

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

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

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

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

17 Then the next paragraph:

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

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

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

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

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

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

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

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

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

10 **A.** Yes, it does. Yes.

11 **Q.** And then:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

25 Obviously, there were people that later we

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

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

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

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

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

3 **A.** Yes, yes.

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

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

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

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

21 **Q.** To consider whether the need justifies it.

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

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

25 "... Trustees of course retain discretion to go

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

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

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

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

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

13 **A.** Exactly.

14 **Q.** -- scheme.

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

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

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

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

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

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1 outside the limits ..."

2 Do you have that?

3 **A.** Yes. Yes.

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

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

7 "... and Trust resources will permit."

8 **A.** Yes.

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

11 **A.** Yes.

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

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

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

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

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

3 Then it says:

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

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

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

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

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

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

7 Then a few paragraphs down, starting:

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

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

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

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

19 Then it says what the application must include:

20 "name and registrant number ...

21 "why you need help

22 "what you need

23 "how much it will cost.

24 "Please remember the following ... points:

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

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

6 **Q.** Then:

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

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

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

20 **A.** I think so, yes.

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

25 "Any information you provide to us about the

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

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

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

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

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

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

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

2 Can you recall why --

3 **A.** Can you show the letter?

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

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

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

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

16 **A.** This is a --

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

18 **A.** Okay, fine. Fine.

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

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

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

11 **Q.** Soumik, can you just show the date on that letter? It's
12 2 October 2002, so a year before you left the Trust.

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

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

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

25 So you are there seeking consent for confidential

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

3 **A.** Not to my knowledge during my tenure.

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

8 **A.** Yes.

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

11 **A.** Yes.

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

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

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

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

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

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

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

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

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

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

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

24 **A.** Okay.

25 **Q.** Did the Macfarlane Trust seek any information from

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1 **A.** Yes.

2 **Q.** And would you --

3 **A.** We would --

4 **Q.** Sorry. Go on.

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

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

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

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

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

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

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

7 **A.** Yes, they are.

8 **Q.** And how were these amounts set?

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

13 **Q.** And did it take account of regional variation?

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

17 **Q.** And what use did the trustees make of these guidelines?

18 Although the trustees had a discretion to allow awards
19 outside the guidelines, given that these prices reflect
20 the average price of the -- whatever is being applied
21 for, were they treated with -- were they quite
22 compelling as to the amount that should be awarded, the
23 trustees?

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

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

7 **Q.** Would you agree --

8 **A.** -- aware --

9 **Q.** Sorry.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

23 **A.** That's it, yes.

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

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

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

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

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

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

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1 requested, and then there's a recommendation. Is that
 2 recommendation the recommendation of the Allocation
 3 Committee or is that the recommendation of the staff
 4 team that goes to the Allocation Committee?
 5 **A.** It's the recommendation of the staff team which sends it
 6 to the Allocation Committee.
 7 **Q.** So the recommendation is:
 8 "To make [the] grant for the excess mileage ...
 9 essential part of his life ...
 10 "... make a contribution towards a cooker and
 11 fridge-freezer if he is unable to secure funding for
 12 these through a community care grant ..."
 13 It notes that Jenny Jackson, who we know from your
 14 previous evidence is the benefits advisor, is currently
 15 applying for one, and:
 16 "To make a grant for the mattress due to issues of
 17 hygiene."
 18 **A.** Yes.
 19 **Q.** So what's the process by which staff come to make these
 20 recommendations? How does one assess the particular
 21 need for these items, if they're not taking into account
 22 financial need? How do they --
 23 **A.** Because they would have received the information almost
 24 certainly from a Haemophilia Centre social worker in
 25 this case. That's my recollection of this particular

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1 would apply on their behalf for one.
 2 If that was turned down, and it was obviously
 3 an essential need, then the full grant would have been
 4 given.
 5 **Q.** Here the recommendation is if the grant is turned down,
 6 to make a contribution towards a cooker. How did staff
 7 determine who would get a contribution and who would get
 8 the full grant when the item that --
 9 **A.** I cannot remember the details of this case, but I'm
 10 quite certain that if the need had been to pay the full
 11 amount for the cooker and the fridge-freezer, if he was
 12 unable to apply for or get any community care grant,
 13 then we would have paid for the whole lot, but I don't
 14 recall the outcome.
 15 **Q.** Was there any guidance that you can recall that set out
 16 how trustees or staff were to assess need on these kinds
 17 of applications?
 18 **A.** I think, as I was hoping to make clear, these grant
 19 applications, as has certainly been an example, would
 20 come through the Haemophilia Centre social worker, or
 21 possibly on occasions the Haemophilia Centre nurse. It
 22 would not have come directly from the registrant or
 23 very, very rarely. If the person was looking for
 24 a holiday grant, for example, even that we would have
 25 expected there to be an accompanying recommendation from

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1 one, and they would not -- it would not be part of the
 2 staff team's responsibility to look into the financial
 3 situation of the particular registrant. They would know
 4 how much regular payments they were getting. They would
 5 know how much benefits, if they were receiving benefits,
 6 they were getting because this would all be on the file.
 7 They would actually also know the number of single
 8 grants that had been applied for and granted.
 9 So they wouldn't need to do that. They wouldn't
 10 need to look for any kind of financial justification,
 11 and neither did they.
 12 **Q.** How then would you or your staff team, looking at these,
 13 decide when to allow -- when to provide the grant in
 14 full or recommend that a contribution is made?
 15 Presumably, in both cases, there's a need for the item.
 16 The question is just how much is going to be given. Was
 17 there any guidance that help the staff?
 18 **A.** Well, a cooker and a fridge-freezer, for example, are
 19 things that the local authority, or I think it's sort
 20 of -- or government, community care grant, you can apply
 21 for from the local authority under that heading, just as
 22 you can apply for adaptations in the house. So it would
 23 be a responsibility to first ensure that that
 24 application had been made or, as is apparent here, Jenny
 25 would -- or the benefits advisor in post at the time

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1 a Centre social worker, or a local authority social
 2 worker, working with the family.
 3 In other words, we didn't assess the need in the
 4 staff group. It would have been a need which would have
 5 been identified by an external social worker, and there
 6 were many occasions when, as a result of that request,
 7 not in this case, Jenny or Fran, or social worker and
 8 benefits adviser, and on rare occasions also
 9 Susan Daniels, the financial adviser, would have visited
 10 a registrant and talked them about the situation.
 11 Now this would not have been necessary in this case
 12 because, apart from applying for the community care
 13 grant, this was an obvious need.
 14 **Q.** Do I understand your evidence to be this: that if
 15 an application was supported by a social worker or
 16 a nurse or indeed the local authority, that would be
 17 sufficient to establish need for the Trust and that
 18 those applications --
 19 **A.** Yes.
 20 **Q.** -- should have been granted?
 21 **A.** If there was any reason to require more information then
 22 the Trust staff would become directly involved.
 23 **Q.** Do I also -- I'm sorry.
 24 **A.** In this situation, it would become immediately apparent
 25 that the cooker and fridge-freezer could be paid for

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1 through a community care grant and possibly the centre
 2 from which this request comes either didn't have or
 3 didn't recognise the need to approach the local
 4 authority for such a grant.
 5 **Q.** Do I also understand your evidence to be that there
 6 wasn't any guidance to help trustees or staff to assess
 7 need because, in fact, they -- I think you were saying
 8 that the need would have been established by the
 9 supporting clinician or social worker who is supporting
 10 an application?
 11 **A.** That's right. If more information was needed, if this
 12 was immediately apparent, then there would have been
 13 contact from one of the office staff and possibly
 14 a visit. I think it's quite clear here that with the
 15 application must have been the obvious need to ensure
 16 the local authority had not been approached for these
 17 things before a grant was given.
 18 **Q.** When applicants were successful, did the Macfarlane
 19 Trust provide vouchers instead of cash or cheques to
 20 registrants to purchase items?
 21 **A.** No, I never remember such a thing being done.
 22 **Q.** I've just got one more question before we break for
 23 lunch and it's this: you say in your witness statement
 24 that later trustees thought that the Macfarlane Trust
 25 was too generous during your tenure, and I just wondered

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1 the trustees, perhaps even the majority, would have been
 2 less generous than you would be inclined to be?
 3 **A.** I don't think it was the majority. I think it was
 4 an opinion that was abroad, and yes, I think so.
 5 **SIR BRIAN LANGSTAFF:** Thank you very much. Well, we'll take
 6 a break now until five past two. So five past two.
 7 Same rules apply, of course, and I look forward to
 8 seeing you back at five past two.

9 (1.05 pm)

(Luncheon Adjournment)

11 (2.05 pm)

12 **MS SCOTT:** Ms Hithersay, can you hear and see me?
 13 **A.** Yes, I can. Thank you.
 14 **Q.** Excellent. Just picking up on some evidence you gave
 15 earlier about debt, when applications were made to clear
 16 debt by applicants, is it right that those would all
 17 have been decided by the trustees because they fell
 18 outside the office guidelines?
 19 **A.** Yes, yes, that's correct.
 20 **Q.** Your recollection, I think, is what you said in evidence
 21 earlier, was that often those applications were dealt
 22 with by way of loan rather than by way of single grant?
 23 **A.** That is correct.
 24 **Q.** Can you recall whether or not there was any policy or
 25 any written guidelines for the trustees setting out when

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1 how you heard that and what you understood that to mean.
 2 **A.** I think that sometimes the trustees did feel that
 3 I would err on the side of generosity if I had any
 4 involvement in making a grant, which was rare. But they
 5 knew that when I spoke about things, such as the
 6 bereavement project, or alternative therapies, or the
 7 need for more support in other ways than financial, that
 8 I was -- they felt I was being a bit over indulgent,
 9 I think. Some of that was hearsay, in fact I suppose
 10 all of it was hearsay, really.
 11 **Q.** When you say all of it was hearsay, do you mean -- what
 12 do you mean? What are you referring to?
 13 **A.** Um ... well, I mean I knew that it was a general climate
 14 in the Trustee Board that perhaps I was encouraging
 15 being over-generous in our responses. I don't believe
 16 that was the case, but I think it was something which
 17 was felt and, after I had retired from the Trust,
 18 I later heard from a member of staff who had retired
 19 that there was some sort of an investigation into the
 20 levels of grants that I had recommended. I don't recall
 21 recommending many grants at all. I don't think it came
 22 to anything.
 23 **MS SCOTT:** Sir, it's just past one o'clock.
 24 **SIR BRIAN LANGSTAFF:** Do I take it that you were personally
 25 aware that, given broadly the same facts, a number of

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1 applications for debt should be acceded to, and in what
 2 form, ie loan or grant?
 3 **A.** No, I can't, because I don't believe there were any
 4 guidelines. It's my recollection, from my
 5 understanding, that it was equity share that was
 6 suggested originally, and in very early cases, and that
 7 subsequently, we received a recommendation from our
 8 solicitors, Paisner & Co, that we should either give
 9 a grant or a loan with a charge on the property, and
 10 that we were, under the trust deed, able to do either of
 11 those things. Equity shares, I don't believe they ever
 12 completely stopped but they were not the best way to
 13 deal with the situation, with hindsight.
 14 **Q.** Soumik can we look at MACF0000065_059. This is a letter
 15 from you -- sorry, not from you, from Macfarlane, to
 16 the, I believe they're your auditors, Pinkney Keith
 17 Gibbs, about loans and secured advances, and it says in
 18 the second paragraph:
 19 "Following the above review" --
 20 The first paragraph:
 21 "Further to your letter ... I went through the
 22 Nominal ledger accounts [this is from Rodney Shepherd,
 23 the finance man] in some detail and have also reviewed
 24 the entries on the individual Purchase Ledger accounts.
 25 "Following the above review, and having checked the

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

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

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

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

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

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

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

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

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

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

8 **A.** They are.

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

12 **A.** To the best of my knowledge, there was no policy. There
13 would have been a discussion at Trustee Board level. It
14 might have been that the original approach from a social
15 worker or the registrant themselves suggested that they
16 would like it as a loan, and they would like to repay
17 it. It might have been that it was decided that it
18 would be best to -- for example, if you look at the
19 4,775 one, to do with a car purchase, I think it was
20 likely that there was no Motability element to which
21 that person would have got a car. She would have
22 clearly needed a car, and so she would have applied
23 probably for a grant -- a regpay advance that she would
24 have paid through regpay in order to obtain a car.

25 I have to say this is supposition and recollection,

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1 were given a loan.

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

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

5 **A.** Yes.

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

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

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

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

3 **Q.** Soumik, if we look at MACF0000088_028, it's a meeting of
4 the Partnership Group, notes of a meeting held on
5 23rd September 1999, and you were attending that
6 meeting. Then if we go halfway down the page, notes of
7 a meeting held on the 14th May 1999:
8 "Issues arising in response to the Notes of the
9 first meeting ..."

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

14 **A.** That's certainly what is suggested there.

15 **Q.** Does that sound right to you?

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

20 **Q.** It may be, if we go over the page to page 2, it may
21 help. "Matters arising" at the bottom of the page,
22 "Membership and Representation":
23 "The issue of the role of the group, and its remit
24 was discussed at some length. It was agreed that whilst
25 members recognised the need for more formal 'user

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

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

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

13 **Q.** Was it successful, in your view?

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

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

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

5 If we go over to page 3, we can see the
6 recommendations for the make-up of the group:
7 "After considerable discussion it was agreed to
8 recommend that the group be made up as follows ..."

9 It sets out the different representative categories
10 of those in the group. Then it says:
11 "It was agreed that Ann and Fran would identify and
12 invite women to fill the roles of Partners and Positive
13 Women."

14 Does that prompt your memory?

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

24 **Q.** What was your --

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

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

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

9 **A.** Not within my tenure.

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

17 **A.** Yes, that was the case.

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

20 **A.** Yes.

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

23 **A.** Yes.

24 **Q.** Were you enthusiastic about user trustees?

25 **A.** Definitely.

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

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

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

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

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

6 **A.** No.

7 **Q.** No?

8 **A.** No.

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

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

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

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

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

25 **A.** No, I don't.

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

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

5 **A.** Almost certainly the chairman and myself, and
6 occasionally the finance officer, and occasionally the
7 treasurer. Usually the chairman and myself.

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

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

11 **Q.** And were those meetings all minuted?

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

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

15 **A.** Yes.

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

19 **A.** Yes.

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

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

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

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

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

9 **MS SCOTT:** Yes.

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

12 **A.** It does surprise me.

13 **SIR BRIAN LANGSTAFF:** Thank you.

14 **A.** It also distresses me.

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

17 **A.** Yes.

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

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

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

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

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

3 But you say this:

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

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

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

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

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

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

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1 Department of Health.

2 **Q.** And did that attitude come through, then, in how they --

3 in the information that they expected from the

4 Macfarlane Trust? Did they expect you to report to them

5 with your spending plans and so on?

6 **A.** We used to discuss a budget every year. We used to seek

7 project funding for particular activities that might

8 have fallen outside the particular budget year or

9 spending plan, like, for example, both the reviews and

10 like, for example, the assistance which was bringing our

11 computerised systems up to date, and later getting new

12 computers, again, because of the -- what was perceived

13 then as the Y2K problem. So there were areas that fell

14 outside what we had discussed in the budget preparation

15 meetings, yes. So we would have presented a project

16 application to them. But we certainly primarily saw

17 them as our main source of funding, our only source of

18 funding, for investment.

19 **Q.** Was the Macfarlane Trust -- did the Macfarlane Trust

20 have to effectively seek the approval of the Department

21 of Health for their policies and spending plans?

22 **A.** I'm not sure about approval as such. What we had to do

23 was to prepare and present a budget, a financial plan.

24 And then that would go through to the relevant part of

25 the Department, and they would approve it, and

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1 I think -- I don't remember them ever not approving

2 it -- there might have been a delay in payment.

3 **Q.** So when you say that the DoH, certainly in the early

4 years, felt that you were administering a fund that had

5 been provided by the Government, how did that -- why did

6 you come to that view? How did that show itself?

7 *(Audio disruption)*

8 **A.** I don't think it was necessarily the Department of

9 Health that held that view. It was certainly the

10 trustee interpretation of the Department of Health's

11 view.

12 **Q.** So the trustees' attitude to the Department of Health

13 was to seek approval, was it, of particular policies, to

14 run things past them, to make sure that the Department

15 of Health didn't have any difficulty with the approach

16 they were taking, and so on? Was that the general

17 approach of the trustees?

18 **A.** Um, I wouldn't have said so. It was very much having

19 a discussion meeting which was minuted, at which we

20 brought up, for example, the changing need of registrant

21 post-1997, or the need for a 10-year review, or later

22 a 15-year review, that kind of thing. They didn't agree

23 or disagree policy areas.

24 When we were making loans, we certainly sought the

25 approval of the Department to do that and their legal

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1 department said, "Yes, this is okay". I don't recall

2 and I wasn't there when the first equity loan

3 arrangements were made so I don't know whether that was

4 floated past the Department or not.

5 Yes, we provided information, they asked questions.

6 I don't believe they ever made any policy guidelines or

7 commented on our policies. From that aspect, we were

8 an independent charity but we were also fulfilling their

9 direction.

10 **Q.** Fulfilling their direction. What do you mean by that?

11 **A.** Spending the funds that were allocated and their

12 direction was that they wanted regular reports on the

13 activities of the Trust --

14 **Q.** Was there ever --

15 **A.** -- and --

16 **Q.** Sorry.

17 **A.** -- those took place in meetings with them, sorry.

18 **Q.** Was there ever -- did you ever encounter any -- the

19 Department -- I think you said they didn't agree or

20 disagree with policies, is that right? They didn't

21 comment on or have input into --

22 **A.** I don't recall that.

23 **Q.** They didn't have any input into any of the policies that

24 Macfarlane drew up or applied?

25 **A.** I don't think so.

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1 **Q.** The Inquiry has seen minutes of board meetings, and

2 certainly at least one during your tenure which we can

3 go to if it's helpful, but where -- Macfarlane Trust

4 board minutes, where Department of Health officials or

5 civil servants have attended. Do you have

6 a recollection of that happening during your tenure?

7 **A.** Was that Sue Bader Malik?

8 **Q.** Let me find it it's MACF0000011_003. It's Mr Robert

9 Finch.

10 **A.** Yes, I do recall Robert Finch attending. I don't recall

11 the context of why he was there but there was certainly

12 nothing -- no reason why from time to time one might not

13 have joined our meeting.

14 **Q.** We can see there 28th May 2002, and you can see where

15 Mr Finch in attendance.

16 **A.** Yes. There certainly was a period, and it could have

17 been about then, when we had a finance trainee from the

18 Department join us on a six-month secondment. It could

19 have been that Robert Finch was connected with that, but

20 I can't recall the detail.

21 **Q.** So you say there's no reason why the Department of

22 Health couldn't attend board meetings. What was the

23 benefit of that attendance?

24 **A.** I can only assume that they wanted a different viewpoint

25 of what was taking place at the -- in the Trust at the

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1 time.

2 **Q.** Do you --

3 **A.** I cannot remember, I'm afraid.

4 **Q.** Do you recall whether the Department of Health got the
5 minutes of the Macfarlane Trust board meetings as
6 a matter of course?

7 **A.** No, I don't believe they did.

8 **Q.** I'm going to move to a new topic now. Soumik, can we
9 have DHSC0004101_048. This is a letter dated
10 29th August 2003 from Dr Hay to you, and he says:
11 "I am very grateful to you for sending us your list
12 of patients with haemophilia who have died and who were
13 HIV positive so that we could reconcile with the
14 National Haemophilia Database and identify any potential
15 discrepancies."
16 Then he goes on to say what he found, that the
17 database had not been notified of 16 deaths and they've
18 amended their records, and that in two cases registered
19 with Macfarlane Trust there was -- they hadn't been
20 notified, the UKHCDO hadn't been notified that they had
21 HIV, and then goes on to look at the circumstances of
22 those two cases.
23 Then picking up towards the end of that paragraph:
24 "When we examined your results, we found that we had
25 records of 70 HIV positive patients who are dead but who

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1 **A.** Yes.

2 **MS SCOTT:** A couple of issues arising from this, this is
3 dated 4th September. You leave the Trust six or seven
4 weeks later.

5 **A.** Yes.

6 **Q.** Can you recall what, if anything, you did in response to
7 the tracing of those 70 families?

8 **A.** I would certainly have made Peter Stevens aware of it.
9 The extent to which I would have delegated action to one
10 of the members of staff, I cannot at this stage recall.
11 Our means of knowing about registrants of the Trust
12 were passed to us by the Department of Health and, most
13 often, through the actual Haemophilia Centres. So I am
14 surprised that it's a very large number, very surprised
15 that Dr Hay didn't apparently know about it, know about
16 some of them. It obviously should have been followed
17 up, and I hope it was but, at that time, there was
18 a great deal going on in the Macfarlane Trust, and
19 I probably didn't put that as a priority. Peter
20 certainly would have known about it.

21 **Q.** Was there a concern at Macfarlane that, given there was
22 a relatively large number of individuals who had never
23 registered, that there may still be some individuals out
24 there, living, who weren't registered? Is that
25 something that the Trust considered?

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1 do not appear in your list. Presumably either they or
2 their relatives did not register with The Macfarlane
3 Trust or possibly they died before the Trust was
4 created."
5 Then sets out some details of those 70 patients.
6 Then we can see your response on 4th September 2003,
7 which, Soumik, is HCDO000612_003. This is your letter
8 in response, 4th September, "Dear Dr Hay", and you thank
9 him in the first paragraph and then a discussion about
10 the two patients who may or may not be HIV positive.
11 Then the paragraph starting:
12 "It would also be very useful to have names of the
13 70 deceased patients not recorded on the Trust's
14 database. This is a large number of people not to be
15 recorded and we need to investigate why and try to trace
16 their families. Even if these patients died before the
17 Trust was set up, payments should have been made by
18 Government to their families. We will certainly pursue
19 the matter on their behalf."
20 **SIR BRIAN LANGSTAFF:** I think perhaps the emphasis there
21 might be "should be made by Government to their
22 families", as opposed to "should have been made". The
23 sense I get from this is that the patients themselves
24 wouldn't have got the money, but their families were
25 entitled to, under the deed.

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1 **A.** Yes, it is a possibility. I would be very sorry if
2 there were children who had been infected, and had -- or
3 indeed widows who had been infected, who had not
4 benefited in any way from the Trust.

5 **Q.** I'm going to ask you --

6 **A.** I see that this is copied to Peter so he would have
7 known about it, and also Mark Winter, and Mark might
8 have had an idea of how we could pursue this.

9 **Q.** I'm going to ask you a handful of questions now about
10 the Eileen Trust, and then The Haemophilia Society.
11 Can we look, Soumik, at EILN0000016_052. This is
12 the Eileen Trust Annual Report from 2002. I just want
13 to get an idea of the numbers of registrants during your
14 employment with the Eileen Trust. So if we can go to
15 page 2 of that document, please.
16 Under the "Trust's operation":
17 "The trust provides assistance to ten registrants
18 (four of whom are single), to two people who were
19 infected by their spouses who had been registrants
20 before their deaths, and to two children who were
21 infected in utero. Assistance is also given to nine
22 families of deceased registrants. Within all these
23 groups there are 12 children aged 18 or under and
24 a further five young people up to 25 years old who could
25 receive financial help from the Trust; four of these 17

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

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

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

12 Then over the page:

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

15 We see halfway down that paragraph:

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

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

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

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

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

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

7 **A.** Yes, that is right.

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

11 **A.** Yes, that's correct.

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

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

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

5 **A.** Yes, I think it likely. Yes.

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

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

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

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

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

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1 certainly was the case at the stage that I joined.

2 There was a great sensitivity about the stigma related
3 at that time to (inaudible)

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

19 **Q.** Soumik, you can take that down. Can we put up
20 CGRA0000852. You can see this a letter from you on
21 28 November, and it's to a registrant of the
22 Eileen Trust. I just wanted to take your -- draw your
23 attention to the big paragraph starting:

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

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

4 That's the capital payment, is it, from the
5 Government in respect of his HIV -- the HIV infection:
6 "... the 'Undertaking' you would be asked to sign
7 would be the Scottish 'Undertaking', not the English
8 one."

9 Then you say at the bottom of that paragraph:
10 "You would be entitled to £23,500 that you would
11 have received in 1991, had you known about the Trust at
12 the time."

13 So is this right, that throughout your time at the
14 Eileen Trust up until 2003, any new registrants coming
15 on to the scheme, the Eileen Trust scheme, still had to
16 sign the waiver that was being signed by registrants in
17 1991 in exactly the same terms; is that is correct?

18 **A.** Yes.

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

22 **A.** That is my recollection, yes.

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

25 **MS SCOTT:** Ah, yes. 28 November 2000.

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

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

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

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

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

4 **MS SCOTT:** Yes.

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

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

22 **Q.** Do you mean the Eileen Trust registrants?

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

13 **A.** Yes, it is.

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

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

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

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

10 **A.** No, I'm sure it wasn't. Obviously, centre directors,
 11 who could have all been on that panel, but I cannot
 12 recall, they would have very much fed information to us.
 13 The World Federation of Haemophilia had congress
 14 every four years, at which a great deal of medical
 15 information was shared amongst the haemophilia community
 16 throughout the world.

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

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

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1 appointment of trustees to the Eileen Trust?

2 **A.** Yes, indeed, to both trusts.

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

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

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

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

22 **THE WITNESS:** Can I just ask something?

23 **SIR BRIAN LANGSTAFF:** Yes, certainly.

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

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1 would have referred to.

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

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

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

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

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

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

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

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1 Would there be scope for this to happen?

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

10 **THE WITNESS:** Thank you.

11 **SIR BRIAN LANGSTAFF:** Quarter to four.
 12 (3.18 pm)

13 (A short break)

14 (3.45 pm)

15 **SIR BRIAN LANGSTAFF:** Yes, Ms Scott?

16 **MS SCOTT:** Can you see and hear me?

17 **A.** Yes, I can.

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

20 **A.** Yes.

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

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- 1 A. Not to the best of my knowledge, no.
 2 Q. Do you know why not?
 3 A. I don't, no.
 4 Q. We looked earlier at some of the different types of
 5 loans that Macfarlane Trust entered into with its
 6 registrants. We looked at the loans by exchange of
 7 letters. Do you know or can you recall whether or not
 8 the registrants entering into those loans were advised
 9 to get legal advice?
 10 A. I can't recall but I think it unlikely.
 11 Q. The same question for those registrants entering into
 12 loans security by legal charge. Were they advised to
 13 get independent legal advice?
 14 A. Again, not to my knowledge. In no way would they have
 15 been discouraged from doing so and common sense would
 16 suggest that perhaps they should have.
 17 **SIR BRIAN LANGSTAFF:** I suppose to ask someone who is
 18 seeking a loan or an equity agreement on their house
 19 because they are short of money, to ask them to obtain
 20 independent legal advice might be to ask them to incur
 21 an expense at lawyers' rates.
 22 Presumably, the only way in which that could be
 23 achieved reasonably would be for the Trust to fund the
 24 advice, would it not?
 25 A. That is certainly one way and it's not something that we

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- 1 eligibility for grants or payments?
 2 A. Not if they were already eligible for those grants and
 3 payments.
 4 Q. So those categories that we looked at, the incapacitated
 5 widow, the widow with children, would not have been
 6 means tested for those, the £100 per month that they got
 7 after the -- six months after bereavement?
 8 A. No, no.
 9 Q. You were explaining in your evidence earlier that the
 10 more proactive approach of the Eileen Trust, in terms of
 11 offering support, anticipating the needs of its
 12 registrants, and the reason that you gave for that or
 13 one of the reasons you gave for that was the fact that
 14 the registrants had less support than the registrants at
 15 the Macfarlane Trust because they weren't associated
 16 with Haemophilia Centres, and so on. What, if any,
 17 consideration was given to the support requirements for
 18 Macfarlane Trust registrants who were not attached to
 19 Haemophilia Centres, for example infected partners or
 20 indeed widows and dependants, or a person with
 21 haemophilia attached to a centre who didn't have
 22 a social worker or nurse who could assist with grant
 23 applications?
 24 So the question is, what consideration was given to
 25 the support requirements of those registrants by

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

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- 1 Macfarlane to anticipate and assist them with obtaining
 2 appropriate funding from the Trust?
 3 A. Obviously we set up a number of groups which would have
 4 brought together those particular categories. We had
 5 opportunities for widows to meet, opportunities for
 6 infected intimates to meet, and we also, as far as
 7 I know, would have made it quite clear to an infected
 8 intimate, widow that she would receive the same
 9 information as anyone, any other registrant of the Trust
 10 after her husband's death.
 11 You refer to people with haemophilia and HIV who
 12 were not attached to a Haemophilia Centre. If they were
 13 registered with the Trust they would have received all
 14 the information that the Trust sent out to all its
 15 registrants.
 16 It wasn't just made available to them through the
 17 Haemophilia Centres; it was made available to them as
 18 individuals. If they missed out on information about --
 19 I cannot really think, but perhaps a particular new
 20 service they should have heard about, I would like
 21 an opportunity to perhaps know what that might be. But
 22 we certainly circulated all our registrants with the
 23 information, regardless of whether or not they were
 24 attached to a Haemophilia Centre and had a social
 25 worker.

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

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

10 **A.** Yes, yes. I think I did.

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

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

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

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

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

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

23 **SIR BRIAN LANGSTAFF:** Yes, thank you very much.

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

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1 those early days at all.

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

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

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

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

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1 registrants which arose from hepatitis C as well as HIV?

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

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

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

13 **Q.** Single payment, yes, sorry.

14 **A.** Yes.

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

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

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1 there would be medical information sought from the
 2 Centre which would be responsible for the treatment
 3 which had led to their infection, I don't know.
 4 **Q.** Were any efforts made to ensure representation on the
 5 Partnership Group or amongst user trustees from the
 6 devolved nations, so for Scotland, Wales, Northern
 7 Ireland?
 8 **A.** I don't believe so. Not necessarily, no. In Scotland,
 9 The Haemophilia Society was a completely separate
 10 charity under different charity rules. In Wales,
 11 I don't think at that point it was a devolved country,
 12 and in Northern Ireland, certainly in my role,
 13 I regarded Northern Ireland as part of the area that we
 14 were responsible for, as I did with Wales, whether or
 15 not the Trustee Board felt the necessity to have
 16 representation from each of those countries, I am
 17 unaware.
 18 **Q.** When you were having meetings with the Government, if
 19 I can put it like that, were they meetings simply with
 20 the Department of Health, or did you have -- do you
 21 recall having any meetings or any interactions with the
 22 Scottish executive after 1999?
 23 **A.** The only occasion I ever recall meeting anyone from the
 24 Scottish executive would have been when I was
 25 a Haemophilia Society trustee and went up to visit. So

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1 **A.** Yes.
 2 **SIR BRIAN LANGSTAFF:** And before you worked for the
 3 Macfarlane Trust and the Eileen Trust, from what you've
 4 said earlier, you were working, I think, essentially
 5 with charities which provided services.
 6 **A.** Yes.
 7 **SIR BRIAN LANGSTAFF:** The difference between those sorts of
 8 charities, and indeed The Haemophilia Society itself, is
 9 that the principal role of the Macfarlane Trust, back to
 10 the Eileen Trust, was as a grant-making charity; am
 11 I right?
 12 **A.** Yes.
 13 **SIR BRIAN LANGSTAFF:** So was that a new experience for you?
 14 **A.** No. We had given grants when I was at -- through the
 15 Blue Peter fund, in fact, when I was at what was then
 16 The Spastics Society. We had certainly fundraised and
 17 sought grants when I was at St Christopher's Fellowship.
 18 So that -- no, it was not an entirely new experience,
 19 but what was new was the source of funding was from one
 20 source only and that the community, the beneficiary
 21 community, was very specific.
 22 **SIR BRIAN LANGSTAFF:** We heard a view expressed not long ago
 23 in this Inquiry that if one had a list, a tariff list,
 24 if you like, of so much for such-and-such a piece of
 25 equipment, just as in the office guidelines, and if it

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1 no.
 2 **Q.** I asked you about emails referring -- that passed
 3 between Peter Stevens and Gordon Clarke earlier.
 4 Another phrase that emerged from emails between trustees
 5 was "whingeing haemos". Do you recall hearing or
 6 seeing, in written communications, anybody using that
 7 phase?
 8 **A.** No, I don't, and if I had, I should have recorded it as
 9 something that I felt was totally wrong and
 10 inappropriate.
 11 **Q.** Do you recall attending any meetings to discuss the use
 12 of derogatory or disparaging terminology used about
 13 registrants and the beneficiary community?
 14 **A.** No, I don't.
 15 **Q.** And do you recall hearing of, or witnessing firsthand,
 16 trustees or staff members referring to members of the
 17 beneficiary community in derogatory terms?
 18 **A.** No. No, I don't.
 19 **MS SCOTT:** Those were all of the questions, sir.
 20 **Questions by SIR BRIAN LANGSTAFF**
 21 **SIR BRIAN LANGSTAFF:** Thank you.
 22 Not long ago in this Inquiry -- well, let me begin,
 23 actually, in this way: you've spent most of your life,
 24 have you, in -- your working life, that is -- in the
 25 charitable sector?

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1 were published to those who were registrants or
 2 beneficiaries that, inevitably, people being people, so
 3 the view went, that they would seek the -- something
 4 which was of the maximum value to the top of the range
 5 for which allowance was being made.
 6 Would that have been your view of this particular
 7 community?
 8 **A.** No, definitely not. First of all, the recommendations
 9 for grants came after careful assessment either by the
 10 Trust's social worker, or a social worker at a centre,
 11 or even a local authority social worker who would assess
 12 the need. There wouldn't be a question of people
 13 necessarily just wanting the most expensive thing on the
 14 list. I don't regard anyone ever regarding that simply
 15 as a shopping list.
 16 **SIR BRIAN LANGSTAFF:** Did you ever see any reason to
 17 distrust, in the main at any rate, the applications made
 18 to the charity for a grant?
 19 **A.** No.
 20 **SIR BRIAN LANGSTAFF:** You took the job, I imagine, at
 21 Macfarlane because you hoped that you would find
 22 fulfilment, personal fulfilment, in occupying that role
 23 in that charity for a period of time; am I right?
 24 **A.** You are right, yes.
 25 **SIR BRIAN LANGSTAFF:** Did you?

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1 A. Yes. Very much so.

2 **SIR BRIAN LANGSTAFF:** Is that why you then -- or why, at

3 about that time, you then went on to become a trustee,

4 voluntarily, unpaid --

5 A. Yes.

6 **SIR BRIAN LANGSTAFF:** -- of The Haemophilia Society itself?

7 A. Yes.

8 **SIR BRIAN LANGSTAFF:** As a matter of interest, had you known

9 Karen Pappenheim from her work in charities prior to

10 your taking up the role with the Macfarlane Trust?

11 A. No, I hadn't. No.

12 **SIR BRIAN LANGSTAFF:** The difference between The Haemophilia

13 Society and its charitable activities and that of the

14 Macfarlane Trust may perhaps have been that The

15 Haemophilia Society felt free to -- indeed, it felt it

16 partly its job to campaign for better treatment by

17 Government of those who had suffered from infected blood

18 products, as well as campaigning in other respects for

19 the general benefit of those who had the condition of

20 haemophilia.

21 That campaigning aspect was broadly absent, was it,

22 from the Macfarlane Trust?

23 A. It was entirely absent. I was certainly told on my very

24 first interview with the trustees that this was

25 a campaigning body, that the fund -- we were

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1 have been handed to me, if I may.

2 **SIR BRIAN LANGSTAFF:** You won't mind? Please go ahead.

3 **MS SCOTT:** The first one is in relation to the childless

4 widow, so the childless widow, the cohort of widows

5 whose support stops after 15 months.

6 Was there any scope for such a widow who

7 subsequently becomes unwell to apply back to the

8 Macfarlane Trust to receive support? So she becomes an

9 incapacitated widow after having her support stopped.

10 Was there any scope for her to apply back in those

11 circumstances?

12 A. She could certainly have applied back. Whether or not

13 she would have been recognised as an incapacitated widow

14 who would need continuing support would have been an

15 individual judgment of the Trustee Board at that time.

16 Q. And are you aware of any steps taken to ensure that

17 widows were aware that they could do so?

18 A. No. Apart from keeping in touch with them and through

19 the Bereavement Project, in particular, we probably

20 would not have known. If they wanted to remain in touch

21 with the Macfarlane Trust, they probably could have done

22 so. But I'm not quite sure what would have been the

23 main avenue for them to keep connected, as it were.

24 Q. So there wasn't a route that springs to mind --

25 A. No.

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1 administering the fund on behalf of Government, and that

2 no liability had ever been admitted by Government, and

3 our role was very specifically to administer the funds

4 for the benefit of the beneficiary group.

5 **SIR BRIAN LANGSTAFF:** Had that approach, the approach of the

6 campaigning for the beneficiary group, been an approach

7 which some of your earlier charities had taken on behalf

8 of their particular communities?

9 A. What, not to campaign?

10 **SIR BRIAN LANGSTAFF:** No, to campaign.

11 A. To campaign? Yes, the previous charities certainly were

12 campaigning. I mean, we had a campaigns department at

13 The Spastics Society, which is now Scope. And we

14 regularly campaigned on the part of homeless young

15 people when I was at St Christopher's. So, yes,

16 campaigning was part of my previous existence.

17 **SIR BRIAN LANGSTAFF:** So a further distinction perhaps

18 between the Macfarlane Trust as a charity and the other

19 charities with which you had association, both before

20 and after your work for Macfarlane, was that they did

21 not feel at all constrained in campaigning on behalf of

22 those whom they served?

23 A. Yes.

24 **SIR BRIAN LANGSTAFF:** Yes. Thank you very much.

25 **MS SCOTT:** Sir, I've just got two further questions that

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1 Q. -- for them to keep in touch.

2 Was the -- we spoke about the Macfarlane Trust

3 handbook, and you, in your evidence, said that it was

4 sent out every year to the registrants. Was it also

5 sent to widows?

6 A. Certainly, if they were infected intimates. I'm not

7 aware of whether we sent it out to all the widows. At

8 this distance of time, I can't recall.

9 **MS SCOTT:** Those are the questions. Thank you.

10 **SIR BRIAN LANGSTAFF:** Thank you very much. Now, is there

11 anything that you would like to say? Feel free.

12 A. Yes.

13 **SIR BRIAN LANGSTAFF:** You can take as long as you like.

14 A. It's a particular area over which I felt concern when

15 I was working at the Trust and have felt continuing

16 concern, and it is one that I don't believe was

17 addressed, as far as I know, by trustees in my time, and

18 I don't know subsequently. It is to do with the area of

19 life insurance.

20 Now, I mean, as you will be aware, anyone who is

21 infected with HIV has, since the inception of the

22 recognition of HIV, has been unable to get life

23 insurance. What I think we failed to recognise was that

24 for almost all mortgages, life insurance is

25 a requirement. Now, I know that Susan Daniels was able

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

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

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

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

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

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

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

14 **THE WITNESS:** Thank you.

15 **(4.20 pm)**

16 **(The hearing adjourned until 10.00 am the following day)**
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1 that's particularly important where people have been
2 living with the results of having had a charge or an
3 equity loan or something else on their property for many
4 years. And, obviously, I'm talking in particular about
5 one lady, but not only. I believe that the whole issue
6 of life insurance was not looked at by the trustees, by
7 Government, to the best of my knowledge, and that the
8 deficit in the lives of people was not recognised
9 because it wasn't looked at. Some questions are too
10 difficult to look at.

11 **SIR BRIAN LANGSTAFF:** Thank you.

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

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

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<p>MS SCOTT: [28] 1/22 15/23 15/25 16/13 26/3 31/8 31/12 33/12 42/16 43/11 44/9 45/21 90/23 91/12 106/9 106/15 115/2 121/25 122/4 131/12 132/16 134/5 139/24 142/19 146/25 147/3 148/9 151/10</p> <p>SIR BRIAN LANGSTAFF: [59] 1/3 1/6 15/21 16/7 16/12 24/5 24/13 24/18 24/23 25/9 25/14 25/24 26/2 31/9 32/16 32/22 42/19 43/10 44/7 45/20 90/24 91/5 106/8 106/10 106/13 114/20 121/23 122/1 131/15 131/23 132/2 132/11 132/15 133/17 134/4 138/2 139/14 139/23 142/21 143/2 143/7 143/13 143/22 144/16 144/20 144/25 145/2 145/6 145/8 145/12 146/5 146/10 146/17 146/24 147/2 148/10 148/13 150/11 151/12</p> <p>THE WITNESS: [5] 1/5 131/22 131/24 132/10 151/14</p> <hr/> <p>'90 [1] 57/17 '93 [1] 57/17 '97 [2] 11/7 18/14 '98 [3] 14/13 17/16 80/22 '99 [3] 11/7 12/1 17/17</p> <p>'capital [1] 55/9 'Undertaking' [2] 121/6 121/7 'user [1] 97/25</p> <hr/> <p>... 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