

Wednesday, 26 May 2021

(10.00 am)

SIR BRIAN LANGSTAFF: Now, Mr Taylor, I'm going to invite you to take the oath in a moment or two, just to remind you that you're talking not just to those you see in front of you and those to your left and to me, but also to a much wider audience, which will number probably over 200 around the country. By the country, I mean the whole of the UK.

SIMON HOWARD TAYLOR (sworn)

Questions by MS FRASER BUTLIN

MS FRASER BUTLIN: Mr Taylor, just before we start, I understand you have your statement in front of you and some notes you may want to use to refresh your memory from.

A. That's correct.

Q. Is there a particular time period when you think your memory might be particularly limited?

A. What, historically?

Q. Yes.

A. Yes, my memory during the sort of '90s in particular, from, sort of, the early '90s through to about '98, '99, at that point I had -- I had HIV and, as a consequence of my HIV infection, my memory is somewhat impaired of that period but not totally.

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A. Yes, I probably was, yes.

Q. Were you receiving publications from them, the Bulletin and things like that?

A. Probably but I don't really recall.

Q. You were co-opted in 1985?

A. Mm-hm.

Q. Then elected onto the Executive Committee in 1986?

A. Yes.

Q. And you served then until 1988?

A. That's right.

Q. Then you served again between 1991 and 1996?

A. That's correct.

Q. And then again between 1998 and 2002?

A. That's right.

Q. In that final period, you were vice chair and treasurer during that time, the different --

A. The final period I was treasurer, I was vice chair in the period between about 1994 to '96 but for the period between '98 and 2002 I was -- for the whole of that period I was the treasurer.

Q. You were also a trustee of the McFarlane Trust --

A. Yes.

Q. -- between 1988 and 1990.

A. That's correct.

Q. All of that was voluntary?

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Q. Before we get onto your roles in The Haemophilia Society, just to set the context, you yourself have severe haemophilia A?

A. Correct.

Q. And you've been co-infected with HIV and hepatitis C --

A. Correct.

Q. -- as a result of blood products?

A. Yes.

Q. You were a member of The Haemophilia Society for a number of years before you were co-opted onto the Executive Committee in 1985; is that right?

A. Well, I hadn't really taken a very active role in the Society before then. I, to some extent, got on with my life, and it was when HIV clearly became a threat and I realised that I would probably be the very person it impacted, I sort of came forward to the Society because I had experience in communications, public relations, lobbying, that kind of thing, effectively to offer my services.

So 1985, when I got involved, that was the first time I was -- really had contact and involvement with the Society.

Q. But before the co-option, were you a member of the Society?

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A. Yes.

Q. Alongside that, you were working full time, as you say, in public relations, communications?

A. I worked in -- I was working very much full time in major public relations agencies where I had a senior role, up until 1992, when, because of increasing ill health, I stopped work and then became freelance.

Q. I'd like to start with when you were a member of the Society, before you were co-opted. And you say in your statement that your perception of the Society at that time was that it was focused on providing information and support to the haemophilia community, is that right?

A. That's correct, yes.

Q. Can you tell us what kind of information you received from the Society in that -- early '80s, late '70s/early '80s time?

A. To be honest, I -- very little. As I say, I'm not sure that my -- funnily enough, my mother was a member, from the earliest days, and she would actually get the documents and I would quite often then read them, but I don't recall that I was receiving regular documents before, much before that.

Q. The Inquiry has heard evidence about the Haemofact leaflets that were produced.

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1 A. Mm.
 2 Q. Do you recall either you receiving them or hearing
 3 about them from your mother?
 4 A. Um, yes, but not in a major way. I wouldn't say they
 5 were a major source of information to me. The major
 6 sources of information to me were what I was reading
 7 in the press, more than anything else at that point,
 8 before I joined -- before I became a trustee.
 9 Q. In your statement, you've said that many people with
 10 haemophilia were isolated, and that often GPs,
 11 dentists and other health professionals were
 12 frequently unequipped and often unwilling to provide
 13 appropriate help and support, and some people with
 14 haemophilia were treated by well meaning but inexpert
 15 haematology consultants with very small cohorts of
 16 haemophilia patients?
 17 A. That's correct.
 18 Q. And you say that the Society played a crucial role in
 19 addressing some of those problems?
 20 A. That's right. Yes.
 21 Q. Was that in part by providing information to patients
 22 so that they knew what treatment they could expect and
 23 perhaps what the risks of treatment were?
 24 A. Absolutely. So one of the core functions of the
 25 Society at that time, and I would probably consider

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1 A. Absolutely not. We were all lay individuals. We had,
 2 for the most part, no scientific or medical training.
 3 Q. But, as a matter of fact, would it be fair to suggest
 4 that patients may have relied on the information to
 5 some degree?
 6 A. Yes. You know, obviously one can't speak for
 7 individuals, other individuals.
 8 Q. But that was your sense, both as a member and in that
 9 early period of --
 10 A. Yes.
 11 Q. -- joining the Committee?
 12 A. Yes.
 13 Q. Could we have the document HCDO0000276_033, please.
 14 We can see this is the annual report of 1986. If we
 15 can turn to page 7, please, Soumik, and the second
 16 paragraph down, we can see that there's discussion of
 17 AIDS being the dominant theme of the last annual
 18 report, and reference in this paragraph to the
 19 attention given to AIDS by national newspapers. Then
 20 in the last sentence of that paragraph, it says:
 21 "A main responsibility of the Society has been
 22 in seeing that errors of fact are corrected and
 23 accurate information made available speedily to our
 24 members."
 25 Would it be fair to say that in 1986, the

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1 probably even to this day, was to enable and empower
 2 people with haemophilia, so that they could know what
 3 to expect from their medical and clinical
 4 professionals and also to provide help and support if
 5 they weren't getting it. So one of the things that
 6 the Society did was to sometimes intervene on behalf
 7 of patients, as it were, to help them if they had
 8 a difficulty with a GP or a dentist or something like
 9 that.
 10 Q. So in terms of the information being provided by the
 11 Society, to their members, what it was your sense of
 12 how much people were relying on that information?
 13 What weight they were putting on that information?
 14 A. I would think not a lot is the short answer. It would
 15 be informative but the primary relationship was always
 16 with the treating physician. And because of the
 17 nature of haemophilia, I believe that people with
 18 haemophilia tended to have very close relationships
 19 with their Centre Director and their Haemophilia
 20 Centre, and whilst it was information, I am not sure
 21 or not convinced that people necessarily relied on it.
 22 But it was to inform the conversation that they would
 23 then have with their doctor.
 24 Q. So there was no sense at all of the Society trying to
 25 replace the role of the doctor providing advice?

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1 Society was seeking to be an authoritative voice on
 2 AIDS and haemophilia to both the members of the
 3 Society and the wider public?
 4 A. Yes, I think that would be fair. As the article
 5 points out, it was a time of alarmist media coverage,
 6 and we would send things out to try and explain, to
 7 reassure people that they couldn't pick up HIV or AIDS
 8 from, you know, sitting in a chair, for example, with
 9 somebody else, and that kind of -- those kinds of
 10 things. Because there actually also -- I think it
 11 might be helpful -- there were very few others at that
 12 stage, the Terrence Higgins Trust the
 13 National AIDS Trust, those were very nascent at that
 14 point.
 15 Q. So there was a sense of the Society needing to fill
 16 a gap?
 17 A. Yes.
 18 Q. Could we then move forward to 1991, WITN4500002. We
 19 pick up the 1991 Bulletin, the fourth Bulletin in 1991
 20 talking about "The Essentials of Haemophilia Care",
 21 and the launch of the new blueprint. The article
 22 starts by discussing the NHS reforms, providing an
 23 opportunity to set out a detailed standard for the
 24 care of all people with haemophilia in the UK.
 25 We can read on, and it says:

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1 "This care is normally provided at present by
2 hospitals in health districts outside that where the
3 individual lives, and so it has been necessary to
4 explain to District Health Authorities ... what they
5 should be buying and where that care should be
6 provided."
7 Then the next column:
8 "The Society's document, 'The Essentials of
9 Haemophilia Care' has been produced in order to assist
10 DHAs in their new task ..."
11 The paper goes on to give guidance on how DHAs
12 should go about -- and it's the next column --
13 contracting for these services.
14 So again, would it be fair to suggest that the
15 Society in this example was seeking to be
16 an authoritative voice in relation to haemophilia care
17 and to educate District Health Authorities on what the
18 Society believed to be the best treatment options?
19 A. Yes, that would have been produced in conjunction with
20 the Haemophilia Centre Directors Organisation, who of
21 course were the medical and clinical specialists. But
22 the objective was to, as you say, make sure that
23 District Health Authorities knew what they should be
24 doing from a commissioning point of view and also
25 again what patients should be able to expect from

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1 were expert in that particular area for advice. You
2 know, but ultimately, then the editor of The Bulletin
3 would work with the -- David Watters and the chairman
4 probably in the final copy, as it were.
5 Q. Could we have HSOC0019583, please. We have here
6 a Bulletin from 1988. And it's the very first
7 article, thanks being recorded for Clive Knight's
8 lengthy time as editor of The Bulletin and other
9 publications.
10 In the second-to-last paragraph we see that it's
11 noted he's:
12 "... continuing to serve on the Publications and
13 External Relations Working Party so his experience and
14 expertise will not be lost."
15 Were you also on that committee, that working
16 party?
17 A. Quite possibly. I don't recall directly, but it is
18 quite possible, yes.
19 Q. And can you tell us anything of what involvement that
20 working party had in the production of The Bulletin?
21 Or other publications?
22 A. I don't recall specifically. Again, we might have
23 acted as sort of subeditors or contribute individual
24 articles but I don't recall particularly.
25 Q. Is it right, then, that the editor, the chairman and

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1 their treating physicians.
2 Q. In your experience of being on the Executive
3 Committee, the Trustee Board as it became later, was
4 that something that carried on throughout your time,
5 of being -- seeking to be an authoritative voice both
6 for the members and for health bodies and for society
7 generally?
8 A. Yes. You know, one of our -- as a health charity, one
9 of our key roles was to advocate on behalf of our
10 community in order to achieve the best possible
11 standards of care, the latest forms of treatment,
12 those kinds of things. And sometimes -- I'm sure
13 we'll talk about it later -- you know, that came into
14 conflict over cost issues and things like that.
15 Q. In terms of the mechanics of producing publications
16 for members, so The Bulletin that we've just looked at
17 and the Haemofacts that we've spoken of, we've heard
18 in other evidence that the Executive Committee had
19 very little involvement in what was put in them. Is
20 that your recollection as well?
21 A. It varied considerably. So it might well be that
22 a small group of the executive assisted with drafting
23 elements of it, but they would also work very closely
24 with specific clinicians. So if a document had
25 a specific remit then we would turn to clinicians who

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1 the coordinator were primarily deciding what articles
2 would be produced, but there might have been some
3 assistance from some Executive Committee members?
4 A. I think that's right. I think the editor would have
5 done most of the heavy lifting, as it were, in terms
6 of writing it. But suggestions from articles would
7 have come from other executive members, from local
8 groups. Individual members, even, would have
9 contributed articles or made suggestions as to
10 content, as it were.
11 Q. And when that content was clinical --
12 A. Yes?
13 Q. -- you said it would have come from a clinician?
14 A. Well, again, it varied enormously. So sometimes it
15 would have come from a -- directly from a clinician,
16 and there are many examples in the evidence of
17 articles by clinicians. If it was a more general
18 article, it might then be written by somebody else on
19 the Executive Committee and then run by a clinician to
20 be checked.
21 Q. If an article was originally written by a clinician,
22 was there any checking of it by another clinician or
23 any form of double checking it?
24 A. No, not that I can recall. Sometimes there would be
25 a sort of consensus view. You know, if it was

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1 a particularly important piece, a number of clinicians
2 might be asked for their input and contribution.
3 Q. And how would one know that from something one was
4 reading in The Bulletin?
5 A. Probably credit would have been given.
6 Q. So if it's authored by one doctor, would it be fair
7 that that article has probably been written by them
8 and not checked by anyone else?
9 A. Probably.
10 Q. But if it's written perhaps by an Executive Committee
11 member but credit is given to these number of doctors,
12 it's probably that there's been an input from those
13 doctors to form a consensus view?
14 A. I don't recall directly but I think it highly likely.
15 Q. With that input from the clinicians in medical
16 articles, was that primarily from the Medical Advisory
17 Panel?
18 A. No, not necessarily. It's -- they were quite often
19 the first port of call. But again, there may well be
20 clinicians who weren't -- didn't happen to be on the
21 Medical Advisory Panel who we knew to have
22 a particular interest or expertise in a particular
23 area. So it would almost all -- it would pretty well
24 always be a Centre Director of a Haemophilia Centre.
25 Occasionally it might be a pure specialist, but it

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1 Advisory Panel that took place in 1991 in just
2 a moment, but in relation to the period before 1991
3 I think you've said that you had no direct dealings
4 with the panel at all during your tenure?
5 A. Not officially. I knew some of them personally or
6 acquaintances with them but not officially.
7 Relationships were usually between the chairman or the
8 general secretary or with the staff, particularly. So
9 either David Watters or, in due course, Graham Barker.
10 They would have had the direct contact with them.
11 Q. So can you help us with this: if the Executive
12 Committee felt they needed advice on a particular
13 issue, how did that reach the Medical Advisory Panel?
14 A. That would be delegated to probably David Watters or
15 Graham Barker, who was the policy manager, and they
16 would seek advice from the Medical Advisory Panel.
17 Q. And then how was the advice conveyed back to the
18 Committee? Did you ever get anything in writing from
19 the clinicians or was it --
20 A. Yes.
21 Q. -- primarily verbal?
22 A. Again, it varied enormously depending on the nature.
23 So, again, I'm sure we'll cover it, but, you know, we
24 would get feedback at executive meetings or policy and
25 group meetings or whatever. But it would probably be

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1 would always be at least a Centre Director.
2 Q. In your statement, you're clear that the Medical
3 Advisory Panel was an advisory panel?
4 A. Mm.
5 Q. And that the Society would make its own policy and
6 decision as it felt fit. Was that the position
7 throughout your time on the Committee or did the
8 Society's interaction and approach with the panel
9 change over time?
10 A. I draw a distinction between what I would call medical
11 and scientific information, where we weren't competent
12 to second-guess the Medical Advisory Panel, and issues
13 relating, for example, to policy on some aspects of
14 treatment. So, for example, in the 1990s, as what
15 became known as high-purity Factor VIII products came
16 in, and then in due course recombinant artificial
17 products, which we use now, came in, we were much more
18 aggressive in calling for their introduction than the
19 Medical Advisory Panel or the Haemophilia Centre
20 Directors organisation were. So one might see, as
21 I say, a slight disconnect in an area like that, but
22 as far as sort of clinical -- sorry, in scientific
23 terms, then, you know, we weren't in a position to, as
24 I say, second-guess them.
25 Q. We're going to come on to the review of the Medical

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1 mostly verbal.
2 Q. I'd just like to unpick a little more about the
3 clinical information that was in some of the Society's
4 publications, and you've addressed the situation for
5 patients in some detail in your witness statement.
6 Could we put that up on the screen so everyone can see
7 what we're looking at. It's WITN4500001 and it's
8 paragraphs 22 and 23 to start with.
9 Page 5, Soumik.
10 Here in paragraph 21 you've talked about:
11 "Responding to the HIV impact on the haemophilia
12 community created a huge range of tasks ..."
13 And then paragraph 22 and 23:
14 "Initially the most urgent need from the
15 community was for information on the threat, and
16 support and advocacy in responding to it."
17 23:
18 "Reliable information was difficult to obtain,
19 both because it was a new and emerging threat about
20 which little was known, but also in the early days
21 there had been differences in opinion by clinicians as
22 to the impact on people with haemophilia."
23 Could you expand on that for us, please? You
24 say there were differences in opinion. What are you
25 addressing there?

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(4) Pages 13 - 16

- 1 A. I think it's an issue which I think the Inquiry has
2 looked at previously, in that there were -- and this
3 is slightly in retrospect, because the -- as I say,
4 I wasn't around in 1983/84, around about that period,
5 but there was -- appeared to me to be -- have been
6 a difference of opinion between some clinicians as to
7 whether or not HIV was a serious threat to people with
8 haemophilia or whether it was something that was going
9 to be confined to the gay and drug use community. And
10 also, there were issues about whether or not there
11 were -- because of the high level of treatment that
12 we'd had, whether that was going to impact. So there
13 was -- it was my perception that there were some --
14 there had been some differences of opinion.
- 15 Q. And was that perception formed when you joined the
16 Society more substantially in 1985/86 or is this
17 a hindsight reflection?
- 18 A. I think it was -- no, I think it was around about that
19 time, because there was -- there was a lot of
20 confusion. There was a lot of uncertainty around the
21 whole issue of HIV. There was uncertainty about
22 its -- elements of its transmission and I just
23 remember that there was a lot of areas of uncertainty.
24 I can't remember detail.
- 25 Q. Were there discussions, then, within the

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- 1 shortage of information from reliable sources, and
2 indeed, as a result of that, I and -- I haven't
3 mentioned it, but I and others from Terrence Higgins
4 Trust sought to set up the National AIDS Trust to
5 provide an authoritative source of information. You
6 know, there was information from doctors, but there
7 was no -- at that point, very many organisations who
8 were saying, you know, "You don't have to worry about
9 sharing your seat with somebody who has got HIV, you
10 don't have to worry about being in the same room as
11 them, you don't" -- and we were dealing with a whole
12 range of issues, which again, clear in the evidence,
13 of children being discriminated against at school, of
14 people who, you know, were not getting medical
15 treatment because of their HIV status.
- 16 And that was the focus of our activities around
17 about that time, was trying to address and deal with
18 situations like that.
- 19 Q. I don't want to put words in your mouth --
- 20 A. No, I'm sure.
- 21 Q. -- but it sounds like you're describing quite a vacuum
22 of information.
- 23 A. Yes, it was a huge vacuum.
- 24 Q. Paragraph 25 of your statement indicates that from
25 your perspective the response to these issues was

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- 1 Executive Committee meeting, or perhaps as the side
2 conversations over coffee afterwards, about those
3 difficulties?
- 4 A. Not particularly. I think the issue that really I'm
5 referring to there is actually probably in the -- you
6 know, the earlier paragraph, 22, you know, was core
7 information about how -- dealing with HIV. And that
8 was the key issue. So people needed to know, you
9 know, were other family members at risk? There was
10 a whole area about, as I say, transmission. And it
11 was those areas particularly I think that we were
12 concentrating on.
- 13 Q. Were you aware of any discussions that reflected back
14 on the advice that the Society had given in '83?
- 15 A. No.
- 16 Q. This was primarily about what was happening in '85?
- 17 A. Yes.
- 18 Q. You also say here that reliable information was
19 difficult to obtain. Can you give us anything more
20 specific on what you're dealing with here?
- 21 A. Again, this is just dealing with HIV specifically as
22 an issue. I can't recall exactly, even though I was
23 later very involved in Terrence Higgins Trust, when
24 that started up. I think it was '94, '95. But again,
25 they only had one member of staff. There was a real

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- 1 a need for regular and rapid communication of
2 information --
- 3 A. Yes.
- 4 Q. -- from a trusted and independent source?
- 5 A. Yes.
- 6 Q. So would it be fair to suggest that the Society was
7 seeking to fill that vacuum --
- 8 A. Yes.
- 9 Q. -- with information?
- 10 A. Yes.
- 11 Q. Would it also be fair, therefore, to suggest that, by
12 filling that vacuum, that they were anticipating that
13 people would rely on the information they were being
14 provided with?
- 15 A. You give people information, it's for them to deal
16 with it. But, you know, we hoped they would.
- 17 Particularly, as I say, in response to HIV at that
18 point.
- 19 Q. How much of this information that you were providing
20 was coming from the Medical Advisory Panel, was coming
21 from clinicians?
- 22 A. It would all have been coming from clinicians. We
23 would have been, sort of, interpreting it, and turning
24 it into lay language which was accessible to people.
25 So I mentioned there, for example, Dr Peter Jones who

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(5) Pages 17 - 20

1 played a leading role in supporting us at that point,
 2 and the publication that he is referred to there, AIDS
 3 and the Blood. It was a very important document
 4 which, in lay terms but in the context of haemophilia,
 5 was made available to members so that they could
 6 understand, as we knew it in 1985, you know, what
 7 having HIV meant for them.

8 Q. In paragraph 23, you've spoken of there being
 9 differences in opinion by clinicians. How did the
 10 Society deal with those differences of opinion? Was
 11 it a situation where the Society had to try to decide
 12 what the consensus was likely to be, or ...

13 A. I think by '95, '96 --

14 Q. '85, '86, I think.

15 A. Sorry, '85, thank you -- '85, '86, you know, there was
 16 less difference of opinion, as information on HIV
 17 became more and more widespread. There was the first
 18 AIDS conference, this became a topic at World
 19 Federation of Haemophilia conferences, and so whilst
 20 my recollection is that, for example, before 1985
 21 there were various disparate thoughts going around,
 22 from about that period onwards, and certainly the
 23 period when I was a trustee, there was much more of
 24 a solid consensus on issues relating to HIV and
 25 haemophilia.

21

1 a Panel at all. It was felt that it was sometimes
 2 difficult for members of MAP to take off their Centre
 3 Directors' hats and give independent advice."

4 Then paragraph 3:
 5 "It was agreed that the Society needs advice and
 6 information on the latest medical and scientific
 7 developments in the fields of both treatment and
 8 research. This advice is needed on both an informal
 9 and formal level.

10 "Informal advice is helpful in formulating
 11 policy and in developing information and advice for
 12 members. Given on an informal basis this advice is
 13 likely to be more independent and less likely to
 14 reflect a possibly false consensus view of the Centre
 15 Directors Organisation."

16 Now, before I ask you in detail about that
 17 document you've actually already addressed it --
 18 you've already addressed it in your witness statement.
 19 Again, it may be useful to have the paragraph on
 20 screen so we can all see it. It's paragraph 71 of the
 21 statement, WITN4500001, page number 14, paragraph 71.
 22 You've said here:
 23 "There was a belief by the Society that it
 24 desperately needed independent, unbiased, expert
 25 medical and scientific advice on the huge issues

23

1 Q. When you became a trustee in 1986 and you'd been
 2 co-opted in 1985, was there any reflection or
 3 discussion about the difference of opinions that had
 4 been in existence before your time?

5 A. Not that I'm aware of. You know, it might be worth
 6 pointing out that most of the trustees at that time
 7 had themselves HIV, and so they would have been
 8 thinking about their own situation. But I'm not aware
 9 of any formal discussions or even informal
 10 discussions.

11 Q. Soumik, could we have HSOC0010470, please. This is
 12 a different document to my reference. If I could just
 13 have a moment.

14 I'm sorry, Soumik, my fault. HSOC0010277.
 15 We're picking up a document in relation to the Medical
 16 Advisory Panel review in 1991. Paragraphs 2 and 3 are
 17 what I want to look at:
 18 "The starting point for this review was the
 19 concern felt by Society representatives attending MAP
 20 that some of the meetings were not a productive use of
 21 their time. There was a feeling that on occasions
 22 both the Medical and Society members of the Panel felt
 23 disappointed with the substantive outcomes from the
 24 meeting. This raised the question as to whether there
 25 was possibly no need to have regular meetings or even

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1 facing the Society. Conversely, there was a belief
 2 amongst members of the MAP that it saw itself as
 3 representing their Haemophilia Centres to the Society.
 4 Consequently, issues such as the cost of new products,
 5 concerns about potential liability and legal actions,
 6 and the innate conservatism of many of the clinicians,
 7 mitigated against them giving honest independent
 8 advice to the Society. There was a view that they
 9 tended to: 'cover their backs' by taking an overly
 10 conservative view of emerging threats; prioritising
 11 issues such as costs and funding; and avoiding
 12 breaking the 'consensus view' of their peers."

13 Was that a reflection of the particular concerns
 14 in 1991, or was it a reflection of concerns that had
 15 been ongoing over a period of time?

16 A. It was ongoing over a period of time, and I noted from
 17 the date of the earlier document that I probably
 18 wasn't actually a trustee at that point. However, I
 19 think there was certainly a sort of conflation between
 20 the role of the Medical Advisory Panel, and the
 21 Haemophilia Centre Directors Organisation, and I think
 22 that, as I say in my statement, that we weren't
 23 necessarily convinced that we were getting from MAP as
 24 a body, necessarily the most helpful information.
 25 We would get it usually from an individual who

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(6) Pages 21 - 24

1 might be a member of the Medical Advisory Panel, but
 2 I think, as a group, it wasn't at that point, I think,
 3 terribly good at sort of coming to a consensus view,
 4 and I think they were influenced by other factors,
 5 which was one of the reasons why we had the review at
 6 that point, and we changed the structure, to some
 7 extent, of the Medical Advisory Panel, and I think
 8 made a clearer distinction between the HCDO as the
 9 Centre Directors running Haemophilia Centres, and the
 10 medical panel.

11 Q. You've talked about the Society desperately needing
 12 independent advice. Was it the sense of the Society
 13 that they -- that prior to 1991 they hadn't received
 14 truly independent advice?

15 A. I think my use of the word "independent" is outside
 16 the Executive Committee.

17 Q. What do you mean by that?

18 A. I mean, we needed advice -- we needed advice from
 19 people who were not trustees of the Society.

20 Q. So you're discussing here the Medical Advisory
 21 Panel --

22 A. Yes.

23 Q. -- and are you suggesting, or were you meaning to say,
 24 that the Society -- that the Executive Committee
 25 hadn't received independent advice from the Medical

25

1 A. Yes.

2 Q. Your statement goes a little further than just that it
 3 wasn't independent, but that it wasn't honest,
 4 independent advice. Can you unpack that for us? What
 5 were you particularly thinking there?

6 A. I think, again, as I say later on in that paragraph,
 7 I think there was a tendency to tone down their advice
 8 or -- rather than necessarily tell us everything that
 9 they thought, that was a sense I had. I can't prove
 10 it, but it was the sense that I had, and I think other
 11 members of the executive had, and we would sometimes,
 12 as I say, outside an MAP meeting, not that I was
 13 directly involved in those meetings, but talking to
 14 a clinician separately or independently one might get
 15 a slightly more forceful view or a more detailed view.
 16 I think that's my interpretation.

17 Q. Final point on this paragraph, Mr Taylor, you also
 18 talk about them "covering their backs". Again, that's
 19 quite striking language. What were you meaning by
 20 that? What were they covering their backs in relation
 21 to?

22 A. I can't remember specifically but, again, my sense
 23 was, as I say there, that they took a more
 24 conservative view. I think it's ... and, you know,
 25 they avoided trying to break a consensus. So I think

27

1 Advisory Panel, that the Medical Advisory Panel hadn't
 2 given truly independent advice?

3 A. Well, I think that, as I say there, that they -- in
 4 the context of the Medical Advisory Panel, I think
 5 they tended to, as I say, quite often take
 6 a conservative position if they wanted to try to get
 7 a consensus. As I say, we tended to get, I think,
 8 better information by talking to people on
 9 an individual basis where they weren't having their
 10 peers peering, dare I say, over their shoulders.

11 Q. Was that a reflection -- sorry, to go back to the
 12 question, but was that a reflection of the situation
 13 going all the way back through to the late '70s, early
 14 '80s?

15 A. I can't -- I don't know. But it was my -- I think
 16 there are two things. I think also the evidence, the
 17 documents I've seen show that there was remarkably
 18 little turnover in the Medical Advisory Panel, that
 19 the people who intended to be on there had been on
 20 there for a very long time, which I think was probably
 21 unhealthy. But I can't comment on what it was
 22 earlier, but that's definitely a sense that I got from
 23 sitting on the Executive Committee.

24 Q. And that was not just your view but the view of the
 25 whole Committee?

26

1 they were, you know, they would take the sort of --
 2 a slightly more lower common denominator approach to
 3 things.

4 SIR BRIAN LANGSTAFF: Just on that, if I may, an overly
 5 conservative view of emerging threats mightn't, on the
 6 face of it, be covering one's back. One might have
 7 thought that taking any emerging threat seriously
 8 might be the way to cover one's back.

9 A. Indeed.

10 SIR BRIAN LANGSTAFF: So by talking about covering one's
 11 back, you're not really speaking here, are you, given
 12 your last answer, of having a conservative view of
 13 emerging threats, so much as worry about breaking
 14 ranks. Is that the point?

15 A. Well, I think, again, there would be a wide range of
 16 issues, so that the application of this would vary by
 17 situation to situation. So for example, in 1991, you
 18 know, hepatitis was becoming an emerging threat, and
 19 becoming an emerging issue, which it had not. It
 20 might have been -- and again, I'm sure we'll cover
 21 this in due course -- that they took a more
 22 conservative view than might have been warranted. But
 23 I think -- you couldn't apply these comments
 24 necessarily to every single situation that we were
 25 dealing with, with the MAP. It would have varied.

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(7) Pages 25 - 28

1 But it was -- I'm reflecting there a sense that I
 2 think I and other members of the Executive had.
 3 **SIR BRIAN LANGSTAFF:** Yes, it was really just the
 4 combination of covering their backs by doing
 5 something. I can understand covering backs and taking
 6 an overly conservative view, but ask ...
 7 **A.** Maybe I was a little sloppy in my writing.
 8 **SIR BRIAN LANGSTAFF:** No, it's your writing and I'm just
 9 trying to understand it.
 10 **A.** No, I think it was -- as I say, I think it was -- we
 11 had a number of different things going on at the same
 12 time. So in some cases they would not want to break
 13 the consensus view. In other cases they might take
 14 a more conservative approach than we would take,
 15 because we would feel on the frontline of emerging
 16 threats. And, you know, it's possible we would come
 17 out of an interaction with them thinking: well, are
 18 they taking this seriously enough? And sometimes
 19 being conservative is a way of, you know, not raising
 20 your head above the parapet and, as I say, taking the
 21 easy approach. I don't know if that helps.
 22 **SIR BRIAN LANGSTAFF:** No, that's quite helpful. Thank
 23 you.
 24 **A.** Thank you.
 25 **MS FRASER BUTLIN:** I want to move on now to the

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1 I hadn't had any interaction with them, I didn't know
 2 them, they didn't know me particularly, or know that I
 3 existed, and so I made myself known to them and said,
 4 you know, "Can I help?"
 5 **Q.** So how would other members of the Society have been
 6 able to influence what the campaign would be or how
 7 the campaign would be run? Was there any opportunity
 8 for members to shape it?
 9 **A.** Yes. There were interactions. So, for example, the
 10 annual meeting, council meetings which were held,
 11 I believe if I recall, twice a year, you know, which
 12 was when sort of ordinary members, if we could use
 13 that term, and representatives of groups would meet
 14 with the Executive Committee. So they'd have an
 15 opportunity at that point. But I think, also, an
 16 awful lot of members were in touch with the Society on
 17 a sort of -- through correspondence and telephone
 18 calls. Apart from asking for information and help,
 19 I think they would have been saying, you know, we need
 20 to do something about this.
 21 **Q.** You also say in your state that the Committee was
 22 informed by political, legal, and the medical advice
 23 given on a personal basis, ie, outside the formal
 24 structure of the MAP, the Medical Advisory Panel, in
 25 relation to the campaign.

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1 HIV campaign.
 2 **A.** Mm-hm.
 3 **Q.** What was the Society campaigning for when you joined
 4 in 1985? What status was the campaign at at the point
 5 that you joined?
 6 **A.** There wasn't really a campaign when I joined. And
 7 indeed, one of the reasons I joined was particularly
 8 for that very reason: you know, professionally, my
 9 professional experience was in communications,
 10 public relations, political lobbying, and one of the
 11 reasons I came forward was because I felt that that
 12 could be helpful to the Society. And I think at that
 13 point there wasn't really -- it was still a question
 14 of coming to terms with this amazing -- this awful,
 15 dreadful thing that had happened. And so it was
 16 probably opportune time for me to get involved, to
 17 help develop, start develop campaigning.
 18 **Q.** Just in terms of how you got involved, did someone
 19 come and talk to you and say, "Look, we'd love to have
 20 you", or was there something in The Bulletin that you
 21 looked at and thought: gosh, I could be really
 22 helpful? As an ordinary member, how did you make that
 23 transition onto the Committee?
 24 **A.** I got in touch with the general secretary,
 25 David Watters, and said, "Hello, here I am". Because

30

1 What medical advice did the Committee receive in
 2 relation to the campaign?
 3 **A.** I particularly -- thinking there, again, of the work
 4 that Peter Jones did in producing supporting materials
 5 that were used in the campaign. And again, there were
 6 documents in the evidence of what the impact was on
 7 people with haemophilia. So -- which we could then
 8 use with opinion formers for media, politicians,
 9 people like that.
 10 **Q.** Did clinicians have any role in saying what the
 11 Society should campaign for?
 12 **A.** No.
 13 **Q.** Could we turn to HSOC0023211, please, Soumik.
 14 We have here an agency brief that you wrote
 15 together with David Watters in February 1987. And if
 16 we turn to page 2, we can see under the heading "Legal
 17 Remedy" where it's said:
 18 "A limited number of legal actions have been
 19 started in the United States against commercial
 20 manufacturers of blood products. Those cases are not
 21 supported by the National Haemophilia Foundation (the
 22 US equivalent of the UK Haemophilia Society) as it is
 23 envisaged that this could bring about problems with
 24 the supply of concentrates in the United States.
 25 Indeed, the concern is that the manufacturers might

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(8) Pages 29 - 32

1 withdraw from the production altogether. While it is
2 the case that in the UK the Central Blood Laboratories
3 Authority produce a considerable amount of
4 concentrates under the National Health Service, this
5 amounts to any (currently) 22% of the UK requirement."

6 Was that concern about supply of concentrates
7 something that was discussed at the Executive
8 Committee in 1987 in relation to whether legal action
9 should be pursued?

10 A. I don't recall -- no, I don't recall.

11 Q. In the next paragraph, there's reference to counsel's
12 opinion having been taken on -- in relation to whether
13 action could be taken on behalf of all the people with
14 haemophilia who were HIV antibody positive. And the
15 indication is that those actions could not succeed in
16 the majority of cases and that a class action wouldn't
17 be possible.

18 Again, why was this put into an agency brief for
19 the campaign? What was the -- why is this put in, in
20 such a central part of it?

21 A. Well, this was a brief to potential public relations
22 or lobbying agencies, to help with the campaign. And
23 it was important that, as one aspect of that campaign,
24 first question which an agency might have asked would
25 have been: well, what about legal action? So it was

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1 A. Yeah.

2 Q. -- that went to the Government? Could we look at
3 that? HSOC0003459, please. My understanding is that
4 you were quite heavily involved in preparing this
5 submission; is that right?

6 A. Yes, yes.

7 Q. If we turn to the first substantial page, the second
8 page of the pdf, we can see the heading "Summary", and
9 in the fourth paragraph down, we see that it's written
10 that:

11 "At Government's suggestion the Society has
12 already explored the question of redress through the
13 legal system ..."

14 Can you tell us about who in the Government had
15 suggested that the Society should explore legal
16 redress?

17 A. Every civil servant and every minister that we spoke
18 to. So, for example and I think I cite, this was
19 repeatedly -- if this was raised in Parliament, the
20 ministerial replies would always be "compensation is
21 a matter for the courts".

22 Q. The paragraph then goes on to say that:

23 "... [the Society] has been advised that claims
24 for compensation as such are most unlikely to succeed
25 because of the difficulty of proving negligence. In

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1 important to explain our understanding at the time of
2 where we were with legal action.

3 And the whole question of litigation over this
4 period obviously became a key issue, and so it was
5 important to brief them on what we understood to be
6 the background and, therefore, why a political
7 campaign, focusing on the moral argument, would
8 probably be more important and was required, rather
9 than just relying on litigation.

10 Q. The two paragraphs we've just looked at make it clear
11 that the Society had counsel's opinion that's
12 negative, but was it also part of the Society's
13 thinking that they didn't want to encourage litigation
14 because they --

15 A. No.

16 Q. -- were concerned about the supply of blood products?

17 A. No, I don't recall that at all. I think -- no,
18 I don't recall that.

19 Q. The campaign got started in the spring of 1987 --

20 A. Mm-hm.

21 Q. -- and then there was some delay because of the
22 General Election.

23 A. Mm-hm.

24 Q. But in the October 1987, a submission was put together
25 by the Society, wasn't it --

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1 any case, the Society is advised that any solution
2 which may be provided by the courts will not be
3 available in the short term. However, the needs of
4 families are immediate."

5 What was the thinking behind putting in
6 a submission to the Government, the fact that the
7 Society had received negative legal advice?

8 A. Because we needed to make it absolutely clear that the
9 legal advice -- sorry. The Government's position that
10 we should pursue a litigation approach, frankly, was
11 an abdication of their responsibilities and it was, to
12 some extent, a sort of 'Get out of jail' card.
13 Because they knew very well that people were dying,
14 and that, by the time the litigation was complete,
15 there would be many, many deaths, and that wasn't
16 going to be an appropriate solution.

17 So it was important for us to say to the
18 Government: what you are suggesting is not reasonable
19 or realistic in providing support for people who
20 urgently need it now.

21 Q. It could be suggested that by telling the Government
22 "We don't have a legal case", that the legal advice is
23 negative, that was strengthening their hand in any
24 negotiations because there wasn't the threat of
25 litigation behind it. What would your response to

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1 that be? Was that something you discussed and thought
 2 about?
 3 A. I don't recall specifically whether or not we
 4 discussed it but, I would say, the -- it was really
 5 important, because they wanted us to go to court
 6 because they knew that it would take years, it would
 7 be very difficult to prove, and we had to say that, as
 8 I say, they were being disingenuous in suggesting
 9 this. And we had to say it, not just -- this was not
 10 a submission just to Government, this was a submission
 11 and a briefing to our politicians of all parties. And
 12 in order to build a consensus, a coalition, rather, of
 13 support, it was important to say the Government have
 14 said this the route we should go down, it's a false
 15 route, and that we need help now and there is
 16 a political and moral argument that they should meet.
 17 Q. There were some members of the Society who were
 18 litigating?
 19 A. Absolutely.
 20 Q. Was there any consideration given to whether this
 21 would undermine their position in the litigation?
 22 A. I think the view was that it wouldn't really make any
 23 difference because the law would be what the law was.
 24 This was a political campaign and, as became clear
 25 after 1987, the two ran in parallel, effectively. So

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1 recompense has been acknowledged."
 2 Then further down the next paragraph:
 3 "Secondly, the allocation of £10 million from
 4 the Treasury to meet some of the financial needs of
 5 those affected is a timely, flexible and compassionate
 6 gesture from the Government."
 7 Then the next paragraph:
 8 "Thirdly, the fact that the fund has been given
 9 into the control of The Haemophilia Society to
 10 administer is attribute to the esteem in which the
 11 Society is held by the public and the Government."
 12 The article carries on to the final page of The
 13 Bulletin which we don't particularly need to go to,
 14 but there's nothing in the article that sets out what
 15 will happen next with the campaign, at this point.
 16 A. No.
 17 Q. Had there been any discussions at that stage --
 18 A. Um --
 19 Q. -- about what we're --
 20 A. Not that -- you know, we're talking about a really
 21 short period of time. We're talking about, you know,
 22 a few weeks. And our focus was very much on, you
 23 know, how do we now -- how do we now respond? I think
 24 that a few months later, then we started thinking
 25 about the next stage.

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1 we had the litigation actions taking place but we also
 2 had the political media and moral campaign going on at
 3 the same time. So we were effectively attacking from
 4 both sides.
 5 Q. This was in October 1987.
 6 A. Yes.
 7 Q. It was really quite a short campaign in the autumn --
 8 A. Yes.
 9 Q. -- because on 16 November 1987, as we know, the fund
 10 of £10 million was announced?
 11 A. Indeed.
 12 Q. After the money was announced to set up what became
 13 the Macfarlane Trust, you've described that there was
 14 then to be a second stage of campaigning --
 15 A. Mm.
 16 Q. -- for further monies.
 17 A. Mm.
 18 Q. Is that right?
 19 A. Yes.
 20 Q. Could we turn to HCDO0000276_043, please, Soumik. We
 21 can see the headline of The Bulletin, it's the fourth
 22 Bulletin of 1987 "It's a start", and as we go through
 23 the article, we can see that there's three points that
 24 are made:
 25 "Firstly, the justice of the Society's call for

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1 Q. Let's look at that together. HSOC --
 2 A. Sorry, could I just add?
 3 Q. Of course.
 4 A. The phrase "It's a start" implied that from day one we
 5 recognised that this was going to be insufficient, and
 6 it was. It was a totally insufficient and inadequate
 7 amount of money. But it was a foot in the door. It
 8 was a recognition of the moral case that we had put,
 9 and that we would be back for more.
 10 Q. And that's what I want to pick up with you, Mr Taylor.
 11 A. Okay.
 12 Q. If we can turn to HSOC0019910.
 13 It's dated 14 December 1987, so very quickly
 14 after the announcement. It's the Haemofact 17, "The
 15 Campaign Continues", and if we go to the last page of
 16 the document, page 4, I think -- that's it -- we can
 17 see the three points that the campaign is going to be
 18 focused on:
 19 "The continuing need for a special weekly
 20 benefit.
 21 "The need to speed up DHSS procedures for
 22 dealing with claims for Attendance Allowance and other
 23 Social Security benefits."
 24 And thirdly:
 25 "The importance of provision for life insurance

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1 and mortgage protection."
 2 And then the note:
 3 "In future, the Government has left the door
 4 open for us to approach them if it becomes apparent
 5 that our needs have not been met. We are confident
 6 that in further representations to the Secretary of
 7 State we shall receive the same consideration as at
 8 our earlier meeting."
 9 Is it fair to say that at this point in time the
 10 Society was not immediately saying, "We need more
 11 money", but the understanding was that if it was
 12 needed then it would be forthcoming?
 13 A. We weren't -- it wasn't guaranteed. And we didn't
 14 really know. I think we might have been seeking to
 15 put words in the minister's mouth, shall we say, by
 16 saying that they would -- you know, they would come
 17 back with more. And the campaign, and the
 18 requirements of the campaign, developed a bit more
 19 over time, as we had more time. But as I say, you
 20 know, in November and December of 1987, there was --
 21 we were sort of overwhelmed with an awful lot of
 22 logistical issues, just dealing with literally -- you
 23 know, I remember the general secretary receiving
 24 a cheque, and thinking: what do I do with a cheque for
 25 £10 million? So it was quite nuts and boltsy at that

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1 "You have said" -- in the future to say, you know,
 2 "You have said that, you know, there might be more
 3 money available."
 4 Q. As you say, you were a trustee of the Macfarlane Trust
 5 from 1988 to 1990?
 6 A. Mm-hm.
 7 Q. In your statement you've said you felt you had to
 8 balance the desire to be generous with the need to
 9 preserve the capital of the fund.
 10 A. Yes.
 11 Q. Why did you consider that the capital of the fund had
 12 to be preserved?
 13 A. Because we hadn't had a firm assurance that more money
 14 would be made available. And that wasn't made
 15 available -- that wasn't made, I believe, until
 16 a meeting, as I say, I think two years later, where
 17 the Government said, "Yes, we will provide additional
 18 funds". So we had to take, to some extent,
 19 a precautionary approach with the capital.
 20 Q. But by taking a precautionary approach, did that not
 21 perhaps mean that the Government wouldn't realise that
 22 there was greater need? Was there any discussion
 23 about that?
 24 A. No. Well, I think the -- again, we had to make
 25 a balance, as I think I said, between being sort of --

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1 stage, as well as dealing with our members, who were
 2 saying "Well, when am I going to get my money?" kind
 3 of thing.

4 So it developed. But we weren't -- whilst we
 5 hoped very much that we would get more money, and I'm
 6 sure feel talk about the Macfarlane Trust maybe later,
 7 you know, we -- that wasn't clear until actually
 8 two years later, I believe, where -- where they did
 9 say yes, there will be some more money, first of all,
 10 for the Macfarlane Trust. And we then went on to
 11 discuss and call for more substantial payments, which
 12 came through in due course.

13 Q. The wording on this document that we're looking at
 14 suggests that there has been some indication from the
 15 Government that there would be more money. Is that
 16 not quite what was happening, or is this is an
 17 accurate representation of the discussions you were
 18 having?

19 A. Well, I wasn't directly involved in the discussions
 20 and I hadn't been involved in the discussion with the
 21 Secretary of State, so I wasn't in a position to say
 22 that. But I think -- I think we were expressing, as
 23 I say, a strong hope, and we were expressing -- we
 24 might be putting an interpretation on it, as I say,
 25 partly to put more pressure on the Government, to say,

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1 showing the Government that we were being responsible
 2 custodians and therefore worthy of more money, whilst
 3 at the same time the Society keeping the political
 4 pressure up, that additional funds should be made
 5 available.

6 Q. In your statement you've described that -- you've
 7 described that:

8 "The [Macfarlane Trust] was independent of the
 9 Government, however the [Macfarlane Trust] was mindful
 10 to ensure that the Government was content in the way
 11 the Trust was being operated, particularly in order to
 12 be in a good position to seek additional funding for
 13 the ongoing work of the Trust."

14 Would you say that the Trust, by and large, saw
 15 itself as implementing decisions of the Department of
 16 Health, or were they independent of it?

17 A. No, we were independent. We made our own decisions.
 18 But as I say, we weren't certain at that point, for
 19 the first year or two, whether additional funding
 20 would be made available. And so we, as I say, had to
 21 balance generosity with -- with, you know, if we don't
 22 get any more money, then we need to make sure that
 23 there is funds ongoing for some considerable time. We
 24 couldn't guarantee it until, as I say, that other
 25 meeting in 1989 where I believe the minister agreed

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1 that there would be additional funding. That changed
 2 the situation for the Macfarlane Trust and we then
 3 realised that additional regular funding would
 4 probably become available and that could change the
 5 situation and the way that the Trust worked.
 6 Q. In seeking to ensure that the Government was content
 7 with how the Trust was operating, was the Trust then
 8 constrained in what it did?
 9 A. I wouldn't say that, but it was important that we were
 10 being seen to act responsibly, you know, with proper
 11 procedures, that kind of thing, is really what I'm --
 12 I think we're getting at.
 13 Q. Did it impact on that decision about how generous the
 14 Trust could be?
 15 A. Well, we could have just given away all the money, but
 16 if -- as I say, without a guarantee of additional
 17 funds then that would not necessarily have been in the
 18 best interests of the beneficiaries, if we'd sort of
 19 blown the cash, as it were.
 20 Q. You spoke a moment ago about the Macfarlane Trust
 21 administering the money --
 22 A. Yes.
 23 Q. -- and the Society putting the pressure on the
 24 Government to increase the funding.
 25 A. Mm.

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1 considering the extent to which matters relating HIV
 2 and AIDS should feature in the Bulletin and Update.
 3 Some readers have suggested that these topics receive
 4 too much attention in these pages.
 5 "Since the advent of AIDS, the Haemophilia
 6 Society as a whole has made strenuous efforts to
 7 maintain a 'One Society' approach for people with
 8 haemophilia -- with and without HIV."
 9 It goes on to discuss what they're going to do
 10 about publications. First of all, can you tell us how
 11 the Society came to hear those comments from members,
 12 how was the Society aware of those different concerns?
 13 A. I would guess that that would have been through
 14 telephone calls, correspondence to the office and to
 15 the officers. So that would have been to the chairman
 16 and to David Watters, people -- there were a lot of
 17 people, a lot of our members, who either because they
 18 were not directly affected by HIV or, indeed, if they
 19 were affected, found the coverage in the Society's
 20 publications what we would now call triggering, and
 21 were -- felt that, as I say, as the article -- as the
 22 editorial says, that we were placing too much emphasis
 23 on it.
 24 I think it's particularly true of cases of -- we
 25 had a lot of -- the Society particularly has always

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1 Q. In relation to the Society, with the benefit of
 2 hindsight, do you think they did enough to press for
 3 more financial support in relation to the Macfarlane
 4 Trust?
 5 A. I would think yes, because the money came. We got the
 6 money. Which is the bottom line.
 7 Q. Do you think they could have done more to get it more
 8 quickly?
 9 A. Political campaigns are uncertain. I think that
 10 a two-year period, the Government wasn't going --
 11 I don't think the Government was going to come back
 12 more quickly than, as I say, a two-year period.
 13 They've said well, you know, "We've given you
 14 £10 million, get on with that", as it were. So
 15 I think it would have been highly unlikely that the
 16 Government would have moved any more quickly,
 17 regardless of what the Society or anybody else had
 18 done.
 19 Q. I just want to explore one further aspect in relation
 20 to the Society. Could you turn with me to -- sorry,
 21 Soumik could we have HCDO000279_004, please. I'd
 22 just like to go to page 2, please. This is
 23 a bulletin, the first Bulletin of 1989 and we can see
 24 in the first two paragraphs, it says:
 25 "The Editorial Board has recently been

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1 catered for families with young children with
 2 haemophilia and because of the nature of the
 3 condition, if you have a child with haemophilia,
 4 particularly if it's not been in the family, you know,
 5 then the family want help and support. And so I think
 6 there was a feeling that lots of talk about HIV and
 7 things like that was not necessarily family friendly.
 8 So -- but as I say, there was some pushback but we
 9 felt that we should keep the balance and, you know, we
 10 had a duty to cover these sorts of issues.
 11 Q. This is obviously talking about the publications?
 12 A. Yes.
 13 Q. Had there also been some pushback about the campaign
 14 that had been run?
 15 A. Yes, indeed. And the -- there were, you know,
 16 elements of the membership who felt that the whole
 17 high profile that -- or the connection that
 18 haemophilia had with HIV was unhelpful, because again,
 19 as I've said elsewhere in my statement, haemophilia
 20 became, in the public perception, a marker for having
 21 HIV or AIDS. And so people who had haemophilia were
 22 finding themselves subject to discrimination and
 23 stigma. Just for having haemophilia. Let alone
 24 having HIV or AIDS.
 25 And so there were -- you know, there were quite

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(12) Pages 45 - 48

1 a few people who felt that they didn't want that high
2 profile. And this happened again in years to come
3 over hepatitis as well. You know, they wanted to just
4 quietly get on with their lives of having haemophilia.
5 **Q.** That's one side of the spectrum. Were there others at
6 the other end of the spectrum who were seeking greater
7 campaigning work from the Society? In relation to
8 HIV; we'll come to hepatitis later.
9 **A.** Um, yes. And we had that constant balancing act
10 between people with HIV who felt that we should be
11 doing much more, and people who did not have HIV who
12 felt that we were already doing too much. And as
13 trustees, we had to balance those, and one never
14 completely succeeds.
15 **MS FRASER BUTLIN:** Sir, I'm about to move on to
16 a different topic and I see the time. I wonder
17 whether now is a good time to take the morning break.
18 **SIR BRIAN LANGSTAFF:** Yes, it is. We'll take a break
19 until quarter to 12.
20 Now, Mr Watters [sic], you may have been
21 watching previous sessions, you will know that on each
22 occasion that there's a break, a first break anyway,
23 I advise the witnesses that at any break they must not
24 discuss the evidence they have given, or may yet be
25 asked to give, whatever else they wish to talk about.

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1 September 1991 was when the Executive Committee
2 started to engage more substantially with the question
3 of non-A, non-B hepatitis and its possible long term
4 consequences. Would that accord with your
5 recollection of that time?
6 **A.** I can't really comment, except that clearly we did,
7 because I was not a trustee until -- I rejoined the
8 board in June 1991 so I'm not aware if there were any
9 discussions prior to that.
10 But clearly the evidence shows that that's when
11 we started looking at the issue --
12 **Q.** More substantially?
13 **A.** -- more substantially.
14 **Q.** Do you know what had caused the Society at that point
15 in time to consider the issue more substantially?
16 **A.** No. Um, no.
17 **Q.** The letter to Dr Hay then sets out a series of
18 questions. It reads:
19 "Our starting point was the need to have some
20 basic information on the scale and nature of the
21 problem. Are we right in thinking, for example, that
22 most (how many?) older patients with severe
23 haemophilia have been infected with hepatitis C at
24 some time in the past? Are we right in thinking that
25 in most cases this is not a problem and that in only

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1 **THE WITNESS:** Indeed. Thank you.
2 **SIR BRIAN LANGSTAFF:** Quarter to 12.
3 (11.15 am)
4 (A short break)
5 (11.46 am)
6 **SIR BRIAN LANGSTAFF:** Yes.
7 **MS FRASER BUTLIN:** I want to turn to the hepatitis project
8 team that was set up in September 1991.
9 Could we have HSOC0003297, please, Soumik.
10 This is an internal memo dated 30 October 1991,
11 indicating that:
12 "At the first meeting to the project team
13 I agreed to write to [Professor] Preston, Dr Hay,
14 Dr Lee and Dr Mayne to test out the ideas we generated
15 at our meeting."
16 Then if we go over the page we have the letter
17 that was sent out, and it's dated 23 September 1991.
18 We can see that this letter has gone to Dr Hay,
19 and it says that:
20 "The Society is beginning to look at the
21 question of hepatitis and haemophilia. As a first
22 stage we have set up a project team to identify
23 possible areas of action and I am writing to you to
24 seek your comments and views on our initial ideas."
25 So it appears from these documents that

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1 a small proportion (15%?) of cases would this result
2 in cirrhosis of the liver, causing death in a few
3 cases. What are the medical problems facing the
4 majority? We want to be able to reassure our members
5 with some simple clear factual statements. We would,
6 in particular like to be able to reassure parents with
7 children under a certain age, that provided they have
8 only received certain blood products they are not at
9 risk of hepatitis. Can we reassure others that
10 although they may have hepatitis they do not require
11 any treatment and that there is little for them to
12 worry about?"
13 How had the project team come to that
14 preliminary view with percentages and an initial view
15 of the seriousness of hepatitis?
16 **A.** I don't recall. Probably because -- as a result of
17 conversations with clinicians.
18 **Q.** If we go over the page we can see in the middle of the
19 page:
20 "On the question of treatment is there anything
21 we can do in terms of promoting certain life styles or
22 habits that might minimise the development of chronic
23 liver disease? Are there certain things that people
24 with hepatitis should not do or avoid?"
25 The fact that the question is being asked in

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(13) Pages 49 - 52

1 this letter in September 1991 might suggest that the
 2 Society hadn't substantially given thought to those
 3 questions before that. What's your recollection of
 4 the previous times when you were on the Committee of
 5 how much engagement there was with hepatitis,
 6 particularly non-A, non-B?

7 A. As I say, I was absent from the board for about two
 8 and a half years or so prior to this. So I'm not
 9 familiar whether there are any conversations. But as
 10 a patient, the conversations with non-A, non-B
 11 hepatitis had been around for -- was a known issue, as
 12 it were, and I was familiar as a result of that. And
 13 again, purely personally, as a patient, one had been
 14 told this kind of thing that it was in most cases
 15 a very long term progression, that it was likely that
 16 there was not going to be -- you know, it was not
 17 a concern for most. That was sort of part of the sort
 18 of day-to-day conversation with one's treating
 19 physician.

20 I believe -- I can't quite recall, but a clear
 21 test for hepatitis C only became available, I think,
 22 around about 1989, but again, I'm not an expert on
 23 that. It was around that period, I think.

24 Q. The Inquiry has heard evidence about the dates for
 25 testing.

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1 "I think you should be very wary of making too
 2 much of a fuss about it and giving it too high profile
 3 since this will just cause distress, and since liver
 4 disease is a much smaller problem than HIV that most
 5 people affected will not suffer any problems from it."

6 That's what Dr Hay's letter said.

7 A. Mm-hm.

8 Q. If we then go to the Executive Committee meeting in
 9 November 1991, HSOC0010385. It's the third page of
 10 the minutes, please, Soumik, under the heading
 11 "Hepatitis".

12 We can see that:

13 "Mr Milne reported that the Project Team
 14 consisting of Mr Dickason and Mr Taylor, along with
 15 Mr Barker and Mr Watters, had completed the brief on
 16 hepatitis. Mr Taylor told the Committee that, having
 17 contacted experts in the field and having received
 18 comprehensive reports on the current thinking of the
 19 subject, the Team had concluded that hepatitis should
 20 not be a major concern for the Society. 80% of people
 21 infected with HCV and HBV would show no clinical signs
 22 and the treatments available were limited; the
 23 understanding of the progression of liver disease
 24 could only be established through liver biopsies, now
 25 considered unethical. The team felt that the Society

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1 A. Yes.

2 Q. If we look at the last paragraph of the letter, we can
 3 see that Mr Barker said that he's written a similar
 4 letter to Dr Mayne, Professor Preston and Dr Lee, as
 5 well as obviously this letter to Dr Hay. Why did it
 6 go to those four doctors? How did the team decide who
 7 it would go to?

8 A. They were all Haemophilia Centre Directors who had
 9 taken a strong interest, as we understood it, in
 10 hepatitis. And so they were naturally the first port
 11 of call, as it were. That's my understanding.

12 Q. If we go to the next page of the document we can see
 13 the start of the reply from Dr Hay, then if we carry
 14 on to the next page, so the body of the letter, and
 15 we're looking at the penultimate paragraph, in the
 16 middle of that paragraph, it says:

17 "For older patients, only qualified reassurance
 18 can be provided that the majority, probably of the
 19 order of 80-85%, will never suffer any problems from
 20 liver disease."

21 Then if we carry on to page 8, and the bottom
 22 paragraph of that, he says:

23 "I think maybe a haemophilia factsheet about
 24 liver disease would be reasonable."

25 Then a little further on:

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1 was in danger of creating concern and worry where they
 2 need not exist. Publicity and high profile coverage
 3 would be out of proportion to the threat that actually
 4 existed. Mr Taylor proposed that a factsheet on
 5 hepatitis be prepared and a request made that the
 6 Project Team be discharged from its duties; the
 7 Committee agreed ..."

8 So we can see that what you said in the
 9 Executive Committee meeting, or what's recorded in the
 10 minutes, appears to reflect and mirror what Dr Hay had
 11 provided in his letter. Is that fair?

12 A. Absolutely. And indeed, a non-expert reading of the
 13 other letters as well.

14 Q. It also mirrored what Dr Lee had said?

15 A. Yes.

16 Q. Could we then go back to HSOC0003297, which is the
 17 same document we were on a moment ago, and go on to
 18 page 14 of the pdf. And we come to the letter from
 19 Professor Preston.

20 If we look at the second paragraph, halfway down
 21 that paragraph, we see that Professor Preston says:

22 "Most authorities accept that, of those
 23 individuals who have been exposed to the hepatitis C
 24 virus, 50% will develop chronic liver disease and that
 25 approximately 20% of these patients will have

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(14) Pages 53 - 56

1 cirrhosis of the liver. There is also now increasing
 2 evidence that hepatocellular carcinoma is
 3 a complication of chronic HCV liver disease."
 4 So Professor Preston appears to be giving rather
 5 different statistics to Dr Hay in his letter, is that
 6 fair?
 7 **A.** Um, slightly. I think -- and again, I'm not
 8 a hepatologist, but chronic liver disease was
 9 referenced in Dr Hay and Dr Lee's evidence. And
 10 I think the 20% -- the key figure there is the 20%,
 11 which I think accords with effectively what was then
 12 reported back as being the population which might have
 13 significant problems.
 14 **Q.** Well, in Dr Hay's letter, he indicated that probably
 15 of the order of 80% to 85% will never suffer any
 16 problems from liver disease. That is quite
 17 a different statistic to 50% developing chronic liver
 18 disease, isn't it?
 19 **A.** Probably. Again, I'm not an expert --
 20 **SIR BRIAN LANGSTAFF:** Well, you don't have to be an
 21 expert, do you, to understand that 15% not having
 22 problems is rather different from 50%?
 23 **A.** I think -- I think my interpretation or my
 24 understanding was that the chronic liver disease need
 25 not necessarily cause significant problems. And that

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1 **Q.** With the benefit of hindsight, in relation to that
 2 early period, that initial period, do you consider
 3 that the risks of hepatitis C were downplayed in the
 4 information that was provided to the Society by some
 5 clinicians?
 6 **A.** I think that's probably the case, and I think it's
 7 notable that whilst the group was formally stood down,
 8 within a few months, from the beginning of the
 9 following year, it was resurrected again because
 10 I think more information was coming forward and it was
 11 developed. But I think you're right. I think that
 12 the tendency was for clinicians -- and again, speaking
 13 purely personally, as somebody who would be talking to
 14 my clinician, the general sense was: look, this is not
 15 something particularly for you to worry about.
 16 **Q.** And do you think that because you'd had those
 17 discussions with your own clinician, that might have
 18 influenced how you read the information from
 19 Professor Preston or Dr Hay and which you gave greater
 20 credence to?
 21 **A.** That's possible, but I wouldn't have been alone.
 22 Again, you know, we were all -- well, some of us were
 23 patients, so, again, we would have had those
 24 conversations. You know, that's always possible.
 25 **Q.** You said a moment ago that the team was resurrected

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1 was what the other doctors were saying, I think --
 2 I believe.
 3 **SIR BRIAN LANGSTAFF:** I see.
 4 **MS FRASER BUTLIN:** Was there any discussion at the meeting
 5 of the project team about the fact that you had Dr Hay
 6 saying one statistic and Professor Preston giving
 7 a rather gloomier statistic?
 8 **A.** I don't recall.
 9 **Q.** Was there any -- well, why did the project team decide
 10 to accept Dr Hay's view over Professor Preston's?
 11 **A.** I don't recall specifically but I think it probably
 12 would have been because there was a feeling that that
 13 was the consensus. As I say, I don't think there was
 14 a feeling at the time that the differences were that
 15 significant. But I don't recall the meeting, you
 16 know, specifically.
 17 **Q.** With different opinions from different clinicians, was
 18 there any discussion about the need to explain to
 19 members that the position was not clear-cut?
 20 **A.** I don't recall. I think, you know, the situation did
 21 develop and, fairly soon after this, you know, we
 22 started doing much more activities and -- as
 23 understanding developed. But I don't recall the
 24 discussions taking place at that meeting other than
 25 what is minuted.

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1 and I want to go to that now.
 2 Could we turn to HSOC0017237, please, Soumik.
 3 These are minutes of a meeting of the Policy Committee
 4 on 15 April 1992, and I want to go on to internal
 5 page 4, please. Thank you.
 6 And at the bottom of the page we can see the
 7 heading "Hepatitis", and we can see that:
 8 "Mr Cowe said that in 1991 a Project Team had
 9 looked at hepatitis, reported its findings and been
 10 discharged, but since then concern had been voiced
 11 that the matter was not as cut and dried as had been
 12 thought. A statement of the Society's policy on
 13 hepatitis had appeared in *Update* April 1992, and
 14 a fact sheet was in the pipeline."
 15 Can you help us just in relation to how this
 16 understanding had come about? How was the concern
 17 raised?
 18 **A.** I'm afraid I don't recall.
 19 **Q.** If we then read on it says that:
 20 "Mr Barker said that he thought the Society
 21 should adopt a stronger, more active position as
 22 various developments were taking place, such as the
 23 development and availability of Interferon."
 24 What was meant by him in relation to taking
 25 a "stronger, more active position"?

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(15) Pages 57 - 60

1 A. Again, I don't recall. However, on a reading of that,
 2 I think that that was particularly in context of
 3 making sure that interferon, if appropriate, was made
 4 available to patients. Interferon at the time was an
 5 exceedingly expensive treatment. Many thousands of
 6 pounds. And my belief is that -- and that became an
 7 element of our campaign going forward, was to make
 8 sure that interferon treatment, as I say, if
 9 appropriate, was made available.

10 Q. By 1993, there was a Hepatitis Task Group in play. Do
 11 you recall how that came into being?

12 A. Again, not in any detail. I believe it probably would
 13 have just been a natural progression. Again, as
 14 evidence came to light, as knowledge evolved, then the
 15 Society evolved its response.

16 Q. Soumik, could we --

17 A. In fact -- sorry -- sorry, just -- I do recall, and
 18 it's evidenced, that actually, I was the one who
 19 raised it, that actually we should be doing it more,
 20 in July 1993.

21 Q. Even after the minutes we just looked at, in
 22 July 1993, you felt even more should be done?

23 A. Yes.

24 Q. If we could have the -- some minutes that we've got of
 25 a meeting of the Hepatitis Task Group, please.

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1 was agreed whereby a series of meetings could be held
 2 at seven venues throughout the UK where medical and
 3 legal aspects of hepatitis would be presented ..."

4 When it's mentioned that there would be legal
 5 aspects of hepatitis, what was that referring to?

6 A. That was referring to -- at those hepatitis awareness
 7 sessions, we would have a number of speakers. So we
 8 would have somebody from the Society, we would have
 9 a clinician, as we say, from another area, so that
 10 patients didn't feel that necessarily they were having
 11 to talk to their regular physician; they got a second
 12 opinion. But we also, I believe and recall, that we
 13 invited representatives of the law firms who were
 14 pursuing some claims to come and talk about some of
 15 the issues about potential litigation, is my
 16 recollection.

17 Q. Soumik, could we just go to the next page of this
 18 document, in relation to the legal position. It
 19 indicates at the top that:

20 "On the legal front it was agreed that, subject
 21 to approval by Committee B, a 'brief' should be
 22 compiled alongside lawyers ..."

23 A. Okay, okay:

24 "... this could then be presented by a member of
 25 the Executive Committee."

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1 Soumik it's HSOC0003289.

2 These are minutes from 16 September, and there
 3 seem to have been three key points addressed.
 4 Firstly, the second paragraph:

5 "It was agreed ..."

6 I think it should say:

7 "... [after] careful consideration that while
 8 there did not appear to be a basis for a generalised
 9 compensation campaign on the basis of presently held
 10 information, this should be kept under close review
 11 both in this country and with other WFH NMOs
 12 throughout the world."

13 Then secondly, under "Possible future
 14 activities":

15 "It was agreed that the most valuable roles
 16 which could be provided by the Society lay in the
 17 provision of accurate and up to the minute advice and
 18 information and an ongoing lobby to ensure the very
 19 best levels of treatment and care of people with
 20 haemophilia and hepatitis in any/all its form along
 21 with support for those who are and become ill."

22 Then finally, towards the end of the page:

23 "The meeting then went on to discuss
 24 recommendations for a Hepatitis Awareness Campaign for
 25 [People With Haemophilia]. After discussion a format

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1 Was that what actually took place or do you
 2 think that --

3 A. I think that is correct, yes. Sorry, my memory is not
 4 perfect in this, but I think, yes, that does --

5 Q. My apologies, I should have gone to that first.

6 A. No, no, no.

7 Q. Why was the hepatitis task group considering adding in
 8 the legal side to the issues?

9 A. That was simply because people were interested in it.
 10 So it was an opportunity -- these meetings were
 11 an opportunity for members to ask questions and raise
 12 issues, and a number of them were asking about
 13 litigation, and so we felt it was appropriate to touch
 14 on that as part of the session, as it were.

15 Q. In relation to the clinical information, as you say,
 16 at the bottom of the page it indicates that home
 17 players wouldn't be used --

18 A. Mm.

19 Q. -- so that there would be an informal second opinion.
 20 Can you explain why it was felt that home players
 21 shouldn't be used?

22 A. That was, as I said earlier, it was really to be able
 23 to give a slightly different -- the nature of the
 24 relationship between many patients and their doctor
 25 was a very long-term one and sometimes a very close

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(16) Pages 61 - 64

1 one. And we felt that it would be -- people might be
 2 able to ask more difficult questions of a doctor who
 3 they weren't seeing on a regular basis, and things
 4 like that, but we felt that it might just facilitate
 5 a much more freedom of discussion in the Q&A which
 6 individuals might have.

7 **Q.** How did the group decide which clinicians would be
 8 asked to do these sessions?

9 **A.** I don't recall specifically. I think it would have
 10 been a combination of availability, which clinicians
 11 were willing to do it and things like that and also
 12 which clinicians probably had some expertise in
 13 hepatitis. But I don't recall the specifics.

14 **Q.** Was there any discussion about the fact that some
 15 clinicians considered hepatitis to be a greater
 16 problem than others, that there were varying opinions
 17 between clinicians?

18 **A.** I have no recollection of that discussion.

19 **Q.** Going back to the very first point on the minutes, the
 20 point that there didn't appear to be a basis for
 21 a generalised compensation campaign, why was that the
 22 view of the group?

23 **SIR BRIAN LANGSTAFF:** Are we still looking at this on the
 24 screen?

25 **MS FRASER BUTLIN:** We are just going back to the top of

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1 Do you recall what those concerns were?

2 **A.** No.

3 **Q.** Under f), we see:

4 "No consensus amongst solicitors on the question
 5 of medical negligence ..."

6 And:

7 "The hepatitis task group recommended that the
 8 Executive Committee discuss a proposal for a
 9 hepatitis C publicity campaign whose objective it
 10 would be to gain better treatment and care for those
 11 infected and financial help from the Government as and
 12 when those infected became ill. The Services
 13 Committee [which was the meeting] was invited to
 14 comment on these proposals."

15 We then have views expressed.

16 If we can go over the page please, Soumik, we
 17 can see your view noted in the minutes:

18 "Simon Taylor concluded the discussion by
 19 suggesting that the Society should make it clear to
 20 ministers and the Department of Health that it takes
 21 the situation extremely seriously. Pressure should be
 22 put onto them, possibly through occasional media
 23 coverage. A high profile campaign was not yet
 24 appropriate."

25 Why was that your view at the time?

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1 it, sir. Apologies. The second paragraph. No, I'm
 2 sorry, the page before, Soumik, the second paragraph.
 3 Why was that the view?

4 **A.** I think again, my recollection isn't complete.
 5 However, I think the feeling was that this was a much
 6 more complex issue in some cases than HIV. Whilst the
 7 root cause of the hepatitis C infection was the same,
 8 which was the, you know, failure of Government policy
 9 and the failure to have self-sufficiency. I think
 10 there were complications because the time of infection
 11 might have been much earlier, might have been --
 12 people might have been affected in the 1970s. And
 13 I think that the legal advice that we'd been getting
 14 was pointed out that it was going to be very difficult
 15 to show direct negligence or, indeed, to identify who
 16 might be the defendant, as it were. So again, we were
 17 dealing with a period of uncertainty at that point.
 18 I would suggest it was the background to that
 19 (inaudible).

20 **Q.** That was September 1993. Could we now turn to
 21 HSOC0023353, we're going on to 1994. If we look
 22 toward the bottom of the page we can see a report from
 23 the Hepatitis Task Group, and at point e), we see
 24 a letter was to be sent to all Centre Directors
 25 "expressing Society concerns on HCV".

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1 **A.** I think the case was not clear but I'd also point to
 2 other comments in the discussion, where there was --
 3 a lot of concern was raised about the potential
 4 adverse consequences of the campaign and the feedback
 5 again that we had had from individuals about linking
 6 hepatitis with haemophilia and also the lack of
 7 knowledge about hepatitis in the community at large.
 8 The media represented hepatitis C as being the new
 9 HIV, and there was a lot of feeling that we
 10 shouldn't -- we should be very careful about going
 11 down that route.

12 Other than that, I think that's all I can
 13 comment on, from my memory.

14 **Q.** A few entries above your -- what you'd said being
 15 noted, there's an entry where Norma Guy said -- it's
 16 noted that she:

17 "... suggested that the Society would have to be
 18 seen to be actively dealing with the issue of
 19 hepatitis otherwise members such as the Manor House
 20 Group may approach the press themselves."

21 And then she also goes on to say that -- it's
 22 noted that she:

23 "... expressed concern regarding the
 24 dissatisfaction of the Manor House Group, if the
 25 Society was not seen to be doing something. In

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(17) Pages 65 - 68

1 response to this David Evans stressed that the Society
2 was clearly attempting to provide more information and
3 promote better treatment for its members."

4 What do you recall of that discussion and how
5 relevant it was that there was group of people who
6 wanted to have a much stronger campaign?

7 A. I don't recall anything of the meeting other than what
8 is minuted, first of all, I should say. I think, as
9 with so many cases, we -- we had to balance different
10 opinions. You know, there were individuals, the Manor
11 House Group, who quite understandably and quite
12 rightly were pressing for more action, and we also had
13 members who were pressing us to not take action. So
14 we were between a rock and a hard place, as they say.
15 As it turned out, and fairly shortly thereafter, you
16 know, we then moved into taking a much more
17 high-profile approach.

18 Q. Soumik could we move on to HSOC0021550, please.

19 We can see this is a press release from
20 November 1994. Were you involved in the drafting
21 of it?

22 A. I don't recall but it's quite possible.

23 Q. It says in the second and third paragraphs that:

24 "The vast majority of people have had the
25 condition for some decades, are well, and every

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1 support. I have a feeling that this press release,
2 and indeed there's another document a few days later,
3 which is a motion passed at our council, was in
4 response to some specific high profile media story,
5 but -- I don't recall specifically but that's my sense
6 of it.

7 Q. Could we then turn to HSOC001 -- sorry, Soumik, let me
8 start again. HSOC0016972, please.

9 We can see here that it starts with a campaign
10 group meeting in January '95.

11 I want to carry on to page 3, please, Soumik.

12 Which is a progress report in relation to the
13 hepatitis C campaign, and it's dated 7 December 1994.
14 So we're at the end of December.

15 So by then a campaign group had been
16 established, and you were a member of it.

17 A. Mm-hm.

18 Q. What had changed between November '94 and
19 December '94, such that a campaign group was set up?

20 A. I don't recall anything specific but clearly we had
21 reflected on the situation, and decided to, you
22 know -- that we should move forward with an active
23 campaign. But I don't recall the specifics. But as
24 you point out, you know, this was -- in terms of
25 a voluntary organisation, with volunteers, six weeks

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1 indication is that they will remain so. A small
2 proportion have had severe problems, and we are taking
3 all appropriate measures to ensure that those affected
4 have the maximum amount of information and the best
5 possible care.

6 "We have no plans to seek compensation from the
7 government, our priority is to ensure help and support
8 for people who are unwell as a result of hepatitis C."

9 Is there a connection between those
10 two paragraphs? And by that, I mean in the second
11 paragraph there is a discussion that it's only going
12 to affect a small proportion of people, only "a small
13 proportion [will have] severe problems", and in the
14 next, it indicates that there are "no plans to seek
15 compensation". Was it the case that the Society
16 wasn't seeking compensation because of the belief that
17 it was only going to affect a small --

18 A. No.

19 Q. -- proportion of people?

20 A. No, absolutely not. The fact that, you know, even if
21 had only been a very small number of people and -- you
22 know, we would have acted on their behalf. I don't
23 recall quite why we said we had no plans to seek
24 compensation from the Government, and shortly
25 thereafter we started campaigning for financial

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1 was a pretty short period to start getting up to speed
2 with a potential major campaign.

3 Q. And if we look at paragraph 2 under the heading
4 "Meeting with [Department] of Health" --

5 A. Yes.

6 Q. -- we can see that:

7 "An informal meeting (ST and GB) ..."
8 So yourself and Mr Barker?

9 A. Mm-hm.

10 Q. "... was held with Tom Kelly at the Department of
11 Health to explain current position. Our concerns and
12 wishes from Government spelt out in broad terms. This
13 contact will be continued. [Department] very happy
14 with Society that not seeking compensation."

15 Why did you inform the Department of Health in
16 an informal meeting that the Society was not seeking
17 compensation for its members?

18 A. I don't recall. And, you know, I've looked at that
19 and I really do not -- it's the same statement as in
20 the press release, so we had already publicly stated
21 six weeks earlier that we were not seeking
22 compensation. I do not have any recollection as to
23 why we had said that, and I fear I don't recall the
24 meeting with Tom Kelly, although it clearly happened.

25 Q. Tactically, in hindsight, would this have reduced your

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1 firepower, your strength -- position of strength with
 2 the Department of Health?
 3 A. No, I don't think it would, because, you know, we --
 4 effectively we changed our mind fairly quickly
 5 thereafter, when we started seeking financial support
 6 for people. So I don't think it made any difference,
 7 particularly. But I would like to remember -- I wish
 8 I could remember quite why we said that.
 9 Q. And indeed, if we go back to the beginning of this
 10 document, to the January '95 notes of the campaign
 11 group, in the middle of the page we've got a heading
 12 "Clarification Of What The Society Wants", and we can
 13 see --
 14 A. Ah, right, there we are.
 15 Q. -- that in January '95:
 16 "Financial help to individuals is one of
 17 4 objectives ..."
 18 A. Yes.
 19 Q. And (b) and (c) then deal with seeking:
 20 "More equitable treatment between HCV infected
 21 and HIV infected."
 22 And then:
 23 "Modification of [the] Macfarlane Trust
 24 deeds ..."
 25 Having told the Department of Health in December

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1 A. But, as I say, I don't recall specifically, but that's
 2 my belief in the kind of thinking which probably would
 3 have been taking place.
 4 Q. They were the meetings from January 1995, and we know
 5 that the campaign was officially launched on
 6 14 March 1995.
 7 A. Mm-hm.
 8 Q. Then you served on the Executive Committee until
 9 1996 --
 10 A. Correct.
 11 Q. -- before stepping down in 1998?
 12 A. Correct.
 13 Q. During that period, from March 1995 until you stepped
 14 down in 1996, how successful would you say the
 15 campaign was over that time?
 16 A. In terms of outcomes, it was not very successful.
 17 I don't recall. In terms of what I might call inputs,
 18 ie, the effort put into it, I think it was quite
 19 considerable, you know, but the letters to MPs, you
 20 know, the representations to Government, use of the
 21 media and things like that, you know, I think we made
 22 a considerable effort during the course of the
 23 campaign, you know, in that period.
 24 But I don't recall specifically that -- I think
 25 the one thing it might have done, if I recollect, is

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1 in an informal meeting, and indeed, as you say, in the
 2 press release, that you were not seeking compensation,
 3 at what stage did you then go back to them and say,
 4 "We are seeking financial help"?
 5 A. This is the same document, isn't it? It's just an
 6 earlier part of it. I just want to have the timeline
 7 right in my mind.
 8 Q. Of course.
 9 A. I would imagine that we -- sorry, I've got to be more
 10 specific.
 11 I do not recall directly. However, I think that
 12 the line of thinking was probably similar to which --
 13 that which had been through the HIV campaign, which
 14 was that if we started talking about compensation,
 15 they would parrot back the same statement that they
 16 had said about HIV, which is, "Well, sue us, then. Go
 17 to the courts."
 18 So I'm thinking that, in all probability, we
 19 were seeking, as I say, a similar approach to that
 20 which we'd taken with HIV, which was to seek financial
 21 support, which might have allowed the Government, how
 22 shall we put it, a way out, as it were, rather than
 23 backing them into the litigation corner, if that makes
 24 sense.
 25 Q. So that was January 1995.

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1 that we might have got agreement on funding for
 2 interferon. I believe that we got that, yes. So in
 3 March 1996 we got the Government achieved -- agreed
 4 that they would provide funding for interferon
 5 treatment for indicated people with haemophilia and
 6 hepatitis C.
 7 Q. The campaign continued even while you were not on the
 8 Executive Committee --
 9 A. Mm.
 10 Q. -- and you returned in 1998.
 11 A. Correct.
 12 Q. I want to move on to September 2000.
 13 A. Right.
 14 Q. By then, there were ongoing questions about whether
 15 the Society should be continuing with the hepatitis C
 16 campaign.
 17 Soumik, please can we have HSOC0000365. I'm
 18 afraid I think I've given you the wrong reference.
 19 Just a moment, Soumik. I hadn't -- it is that
 20 reference. HSOC0000365, but it's the second page of
 21 the document, please.
 22 We have here a lengthy letter that you wrote to
 23 Chris Hodgson in September 2000, and you're placing on
 24 record, you say, four points. The first, under
 25 number 1:

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1 "As I made clear at the Board meeting held
2 12 September, I cannot support the political campaign
3 for financial assistance for those affected by HCV.
4 This is primarily because I believe that, as I set out
5 in my paper presented to the Board, the prospects for
6 success are negligible, and in light of this I cannot
7 justify further expenditure of charitable funds on
8 a campaign which I do not believe can succeed."

9 Can you explain to us why you considered that
10 the campaign was not going to succeed at that point?

11 A. I think, just to put the letter in context and to make
12 it very clear what I say in the very first line, which
13 is I was writing this letter in my capacity as
14 treasurer of the Society. And, regardless of my own
15 personal views on the campaign, on hepatitis, I had
16 a duty to safeguard the funds and assets of the
17 Society.

18 And Karin Pappenheim, who was the chief
19 executive at that point, had earlier raised questions
20 and issues about the campaign, quite rightly, because
21 it's only good practice in any organisation, if you're
22 conducting an activity over a period of time that is
23 taking up a very significant amount of time and
24 resources, that it should be reviewed.

25 And the review which took place in the end of

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1 this judgment, which was shared by a number of
2 trustees, is based on your professional experience.
3 And you go on to say:

4 "Anyone who believes that in the current
5 political climate, we can obtain a reversal of
6 a government policy that has been endorsed by three
7 successive Secretaries of State, in two governments of
8 opposing political persuasions, is deluding
9 themselves."

10 Was it the fact and the nature of response from
11 Government --

12 A. Yes.

13 Q. -- that informed your --

14 A. Yes.

15 Q. -- view that this was not going to succeed?

16 A. Yes. I had a feeling, so professionally, but as
17 I say, we were banging our head against a brick wall.
18 Now, there's nothing wrong with doing that, but it
19 needs to be a conscious decision, as it were.

20 As I say, I would draw a clear distinction
21 between my comments as the treasurer responsible for
22 the assets of a Society from my own view. My own
23 personal view, as somebody living with hepatitis C,
24 was that we should carry on. By then, it became clear
25 that I was not going to die of AIDS but I was then --

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1 1999, I think it was -- what's the date of this
2 letter?

3 Q. September 2000.

4 A. September 2000, sorry. No, during 2000 -- was that
5 the campaign had been hard fought and was being hard
6 fought. However, two governments of different
7 political persuasions had flatly turned us down, and
8 there were a number of other significant factors which
9 were mitigating against the campaign.

10 And so I wrote this letter as a sort of
11 challenge, effectively, to get -- specifically to get
12 legal advice on pursuing the campaign going forward.

13 As you say, I raised a number of different
14 issues, and I felt that it was important that if we
15 were going to go forward, that we had proper what you
16 might call legal cover for it, because we stood the
17 risk of being challenged by our own members for
18 carrying on this campaign, particularly at a time,
19 I recall, that we were running at a deficit, as
20 a charity.

21 So it was, I felt, appropriate to, as I say,
22 raise various concerns which I and others on the
23 Executive Committee had, so that we could get clarity
24 and then we could decide how to go forward.

25 Q. If we read on in this paragraph, you indicate that

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1 so then the next thing I probably would die of is
2 hepatitis C. So, quite personally, I was quite keen
3 that we should continue but I felt that it was
4 important that the Board and the trustees should
5 really take a really long hard look and we were very
6 clear about where we go from here.

7 Q. You've mentioned wanting legal advice to be sought,
8 and we see that in the second paragraph of your
9 letter, that you had asked Karin to seek advice from
10 Paisners as to the legality of pursuing this campaign.

11 A. (Witness nodded)

12 Q. If we can pick that up and go to WITN4500026.

13 What we have here are minutes of the trustee
14 meeting, the Executive Committee having become a Board
15 of Trustees in November 2000, and if we can turn to
16 page 5, please. Thank you. Under the heading
17 "Campaigns". We can see that:

18 "The trustees discussed the advice given by the
19 Society's solicitors in relation to the Society's
20 hepatitis campaign. It was noted that Paisner's
21 advice following from the Charity Commission's
22 guidance is that:

23 '... to ensure that the Society operates within
24 the guidelines ... the trustees would first need to
25 explore the possible success and viability of the

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(20) Pages 77 - 80

1 campaign (both from a financial and legal point of
2 view). It will also be necessary for the Society to
3 obtain medical evidence to support the campaign, and
4 this, together with any legal or other evidence, must
5 be presented objectively and responsibly."

6 At the bottom of the page -- sorry, three
7 paragraphs from the bottom:

8 "There was discussion on the political aspects
9 of the campaign and debate about the aims. The point
10 was made that if higher priority were to be given to
11 campaigning with more resources being dedicated to
12 this activity, this could entail dropping other
13 activities and making cuts in service provision.
14 Trustees would be accountable to members for such
15 decisions."

16 Then at the bottom of the page:

17 "It was agreed to hold the extraordinary meeting
18 on 19 January ... in order to discuss the campaign
19 further and to allow time for external consultants to
20 review the campaign and come up with the costed and
21 time-tabled strategy required."

22 Is that your recollection of what took place?

23 A. Absolutely, and I think the earlier point you make
24 about having to drop other activities, we needed to be
25 clear that we were making conscious decisions about

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1 A. Probably, difficult to say with a hindsight of
2 20 years. But I don't think that necessarily, you
3 know -- it's reasonable, yes.

4 Q. Then at the bottom of the page we can see that:
5 "Following further discussion it was proposed by
6 [you, and then seconded] that:

7 "'The campaign objectives are exclusively:
8 "'a public inquiry into blood borne infections
9 "'a hardship fund which would be a fixed total
10 sum for the benefit of individuals affected by HCV on
11 a case by case basis on evidence of hardship [and]
12 "'recombinant for all'."

13 Just focusing in on the hardship fund objective,
14 why was that change to the campaign made from
15 financial help more broadly to a hardship fund?

16 A. I'm not sure. I don't recall specifically. However,
17 I'm not sure that that distinction was particularly
18 being made.

19 Q. So do you mean by that that this was intended to still
20 encapsulate financial help --

21 A. Yes.

22 Q. -- broadly --

23 A. Yes.

24 Q. -- rather than it being a pure hardship fund?

25 A. Well, I -- I don't recall but it was certainly,

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1 how we deployed our resources and assets. That's the
2 first point.

3 I think the second point was that the legal
4 advice had been that we needed to effectively get
5 experts to sort of assess the campaign, and we then
6 went on and got -- and recruited a leading firm of
7 public affairs consultants to help with the campaign
8 going forward, and that was part of our review
9 process.

10 Q. In terms of that review, we can see the discussion in
11 January 2001.

12 A. Mm.

13 Q. If we could have WITN4500028, please, Soumik. It's
14 page 2, please. Next page, please. Thank you.

15 About halfway down the page we can see the
16 heading "Campaign review", and within that text we can
17 see:

18 "Trustees asked if Politics Direct considered
19 that the Society had had a powerful enough voice in
20 the campaign and Paul Richards replied that he could
21 not find any mistake or issue that had not been
22 covered but that a lack of clearly defined goals was
23 a weakness."

24 Do you think that was a fair assessment of the
25 position with the campaign?

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1 I think, the -- my reading of that is that we were
2 looking at setting up another Macfarlane type
3 organisation. I don't recall that, I'm afraid.

4 Q. And then you finished your time as a trustee in the
5 following year, in 2002?

6 A. Indeed. You know, I'd say that we then went on from
7 there, and, as I say, hired a major agency at some
8 considerable cost. We achieved recombinant for all.
9 The public inquiry, I'm appeared, did not happen until
10 20 years later, but yes.

11 Q. I want to move to a different topic. I want to look
12 with you a little bit about the Society's interaction
13 with BPL and with pharmaceutical companies.

14 You've noted in your statement that the Society
15 reviewed information from BPL and pharmaceutical
16 companies and that -- you said this was valuable to
17 gain an understanding of the products and processes --

18 A. Mm-hm.

19 Q. -- so that the Society could understand product safety
20 and innovations.

21 Could we have a look at HSOC0029476_076.

22 We're going back to 1989. We can see on page 2
23 of these minutes, under the heading "Blood Products",
24 that:

25 "Ken Milne reported that meetings would be held

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1 with representatives of the various pharmaceutical
2 companies over the coming months."
3 And, a little further on, that he would be
4 joined by you at those meetings.
5 Did you in fact attend any of those sorts of
6 meetings?
7 A. No. With one exception: I do recall going to BPL to
8 see their plant at Elstree in order to see the GMP,
9 the good manufacturing processes, which was the main
10 objective of the exercise. So it was a way of trying
11 to reassure us about the safety of the production
12 process of blood products. But in fact, I didn't --
13 I was still in full-time employment at that point, and
14 so my availability and time to go to external meetings
15 during working hours was limited.
16 Q. But others did go to those sorts of meetings, it
17 seems.
18 A. Um --
19 Q. Is that your recollection?
20 A. It's possible. Ken was a scientist by background and
21 I think he would have taken the lead on many of those
22 meetings, but I don't recall who else might have gone.
23 Q. When there'd been a meeting or a visit with
24 a pharmaceutical company or with BPL, was that
25 information then conveyed to the Executive Committee?

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1 companies, I think it was appropriate and necessary
2 that we should occasionally seek opportunities to
3 interrogate them on their processes. Given the
4 history, as it were.
5 Q. And when you've come to speak about funding from
6 pharmaceutical companies, pharmaceutical companies
7 providing funding for things with the Society, you've
8 said in your statement that your view was one of wary
9 cynicism.
10 A. Yes.
11 Q. What do you mean by that?
12 A. We were very clear that, you know, we were very small
13 charity, with very limited resources. And we were
14 aware, with the commercial companies, that they had --
15 were, we believed, complicit, as it were, along with
16 the failure of Government policy, in having infected
17 us all with HIV or hepatitis C. And consequently, you
18 know, we didn't trust them. But we were reasonably
19 happy to take a bit of cash off them, you know, to
20 support our activities in dealing with a situation
21 which they had, in part, caused.
22 Q. Given that the Society was small and, as you say, did
23 accept the funding from the pharmaceutical companies,
24 in the minutes it seems that the funding was for
25 specific activities.

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1 Were they told about what was talked about?
2 A. Um, yes. Probably fairly informally. These were not
3 sort of very formal meetings, they'd be more sort of
4 'get to know' meetings, this is what we're doing. It
5 would have been reported back probably through the
6 Blood Products Committee. But I don't recall
7 specifically.
8 Q. Similarly, when you went to visit BPL, I think in
9 1994, the minutes suggest, did you convey that
10 information back to other members of the Committee?
11 A. I may have done but, again, it wouldn't have been a --
12 it would be more of, you know, "I went to BPL, you
13 know, I couldn't see any mice running around the
14 laboratories". It was a pretty informal kind of
15 process, as it were.
16 Q. In relation to both your visit to BPL and the other
17 visits to pharmaceutical companies, did you and the
18 Committee consider that these organisations might have
19 had a vested interest in showing you that their
20 products were safe? Was there any sense of whether
21 they had an interest in showing you particular things?
22 A. Well, they certainly had a -- I would hope to think
23 that they had an interest in showing everybody that
24 their products were safe. And given the record,
25 particularly, of the commercial pharmaceutical

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1 A. Yes.
2 Q. For publications or seminars.
3 A. Yes, yes.
4 Q. Without that funding, would those activities have
5 taken place?
6 A. It's impossible to say, as to what decision we might
7 have made otherwise. Generally, we would have tried
8 to carry on with those activities. They would be
9 deemed to be priority activities, and we would have
10 tried to carry on doing them. And it was only after
11 we had identified the particular activities that we
12 would go and see if we could get sponsorship.
13 But it's impossible to say what decisions we
14 would have made with resources and priorities, you
15 know, in that hypothetical situation.
16 Q. How did the Society, the Executive Committee or Board
17 of Trustees, address that tension between wanting the
18 money, so that the activities could take place, but
19 what you've described as the cynicism in relation to
20 the pharmaceutical companies?
21 A. I think it was pretty straightforward. The -- I'll be
22 blunt, you know, we would try and screw them for as
23 much as we possibly could.
24 Q. Was the tension discussed? Was it a matter that was
25 spoken of in the Committee, that they weren't to be

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(22) Pages 85 - 88

1 trusted but we'll have their money, thank you very
 2 much?
 3 A. I think it was a general consensus view and, you
 4 know -- I think it was a general consensus view. We
 5 might not have been quite as blunt as I've just put
 6 it.
 7 (Pause)
 8 MS FRASER BUTLIN: Sir, those are the questions I have for
 9 Mr Taylor. I obviously need to see if there are
 10 further questions to be asked from the recognised
 11 legal representatives. We're just ahead of lunchtime.
 12 SIR BRIAN LANGSTAFF: Very well.
 13 Well, we'll take a break now until five to two.
 14 And come back and see what further questions we may
 15 have. That gives you long enough, I think.
 16 MS FRASER BUTLIN: It does. Thank you, sir.
 17 SIR BRIAN LANGSTAFF: Very well. Five to two, Mr Taylor.
 18 (12.49 pm)
 19 (Luncheon adjournment)
 20 (1.55 pm)
 21 (Proceedings delayed)
 22 (2.10 pm)
 23 MS FRASER BUTLIN: Mr Taylor, I have a series of questions
 24 from the recognised legal representatives so they
 25 cover several of the themes, so they may feel a little

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1 expert witnesses in the HIV litigation?
 2 A. I was not aware of that, and I can't -- I don't know
 3 whether the rest of the Committee were aware of that.
 4 Q. So you don't recall any discussion about any possible
 5 conflict of interest in that regard?
 6 A. No, no.
 7 Q. In relation to the decision to openly say to
 8 Government that there were poor prospects of success
 9 on a compensation -- on litigation in relation to HIV,
 10 who made that tactical decision to say that?
 11 A. I would think it was probably a consensus decision to
 12 make it clear to the Government that they were
 13 effectively, as I said, being disingenuous in
 14 proposing a path of action which was not going to
 15 succeed in providing help and support on an immediate
 16 basis to people who urgently needed help and support.
 17 Q. When we were discussing the HIV litigation, we
 18 discussed whether the concerns about supply of
 19 concentrates influenced the Society's position on
 20 litigation. Could we look at HSOC0029476_061, please,
 21 and could we go to page 3.
 22 At the top of the page, "Compensation claims",
 23 we see:
 24 "[The World Federation of Haemophilia] had also
 25 circulated a paper advising against the pursuit of

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1 bit scattergun.
 2 First of all, when you first arrived at the
 3 Society in 1985, what established relationships did
 4 the Society have with non-haemophilia clinicians? For
 5 example, hepatologists or virologists?
 6 A. Probably very few, I think is my recollection because,
 7 up until that time, it hadn't really been an issue, as
 8 it were, but I don't recall that there were,
 9 particularly at that point, strong relationships. As
 10 the HIV -- the impact of the HIV epidemic became more
 11 apparent, then they did have -- they did develop
 12 relationships. So for example, I recall, I think it
 13 was either in 1985 or 1986 at the annual general
 14 meeting, the Society invited Dr Richard Tedder, who
 15 was the leading epidemiologist in HIV, to come and
 16 give a talk. So they did develop as things
 17 progressed.
 18 Q. With the benefit of hindsight, could an independent
 19 medical view, from non-haemophilia clinicians, should
 20 it have been sought sooner?
 21 A. Possibly with hindsight, but again, you know, it's
 22 always easy to look at things in hindsight.
 23 Q. In relation to the Medical Advisory Panel, were you
 24 aware, or was the Committee aware, that several of the
 25 members of the MAP were instructed by the defendant as

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1 compensation claims. This resolution had its base in
 2 the [US] where it was feared that actions brought
 3 against individual pharmaceutical companies could lead
 4 to a 'drying up' of the concentrate supply. Since it
 5 was felt that action against companies in the UK was
 6 only one option -- and perhaps the least likely to
 7 succeed -- it was suggested that we should reserve our
 8 position by voting against the resolution. This was
 9 proposed by Mr Taylor, seconded by Mr Knight and
 10 agreed unanimously."
 11 Do you recall this meeting and this resolution?
 12 A. Not specifically, but I think it goes to show that we
 13 didn't allow the possibility of said drying up or
 14 litigation against companies. We kept that option
 15 open, and we voted against this resolution, in order
 16 to keep that option open. And I don't recall that the
 17 "drying up" of supply was a contributory factor in our
 18 decision making.
 19 Q. This morning we discussed two letters from Dr Hay and
 20 Professor Preston about hepatitis C.
 21 A. Mm.
 22 Q. If we could have HSOC -- sorry, I've got a different,
 23 just a different reference, give me one moment.
 24 HSOC0003297. Yes. Sorry.
 25 And if we could turn to page 4 of the document,

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1 please. When we spoke about whether there was
2 a difference between Dr Hay and Professor Preston, you
3 said that your interpretation, your understanding was
4 that the chronic liver disease need not necessarily
5 cause problems and that there wasn't in fact
6 a difference between the two letters. If you look at
7 the first paragraph of this letter in the middle, it
8 says:

9 "The patients are therefore usually unaware that
10 they have liver disease ... The majority of these
11 patients, if biopsied, have been shown to have chronic
12 persistent hepatitis, a mild and usually
13 non-progressive form of liver disease unlikely to give
14 problems."

15 Is that where your understanding came from?

16 A. Yes.

17 Q. We can take that down. Thank you, Soumik.

18 I have a few questions now about the hepatitis
19 campaign. We spoke about the Macfarlane Trust and the
20 need to maintain a good relationship with the
21 Government in relation to future funding. To what
22 extent was the Society's decision not to advance
23 a hepatitis C campaign in the early '90s based on
24 a desire not to jeopardise continued funding for the
25 HIV population?

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1 A. No, 1996, for hepatitis.

2 **SIR BRIAN LANGSTAFF:** It's gone down as 1986 in the
3 transcript, but that's how I heard it. I thought you
4 meant '96.

5 A. Sorry. Definitely '96.

6 **MS FRASER BUTLIN:** I'm sorry, sir, I heard it as '96 but
7 that's fine, we've corrected the transcript. It is
8 '96.

9 **SIR BRIAN LANGSTAFF:** Good job we're not solicitors then,
10 aren't we?

11 **MS FRASER BUTLIN:** In relation to both the HIV and
12 hepatitis C campaign, you've described it as being
13 a moral case --

14 A. Yes.

15 Q. -- rather than a legal case. Can you explain what you
16 mean by that?

17 A. The moot cause of the reason we're all here today is
18 that -- is that I and the Society has always believed
19 that it was a failure in Government policy.
20 Dr David Owen made the commitment and has given
21 evidence to this Inquiry; he made the commitment in
22 the mid-1970s. And as a physician himself, he
23 recognised the dangers and problems of the blood
24 supply that was coming from the United States, and
25 I think that was a key motive -- well, I know that was

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1 A. I have absolutely no recollection that that was an
2 issue in our thinking at all.

3 Q. And within the hepatitis campaign, was the focus
4 solely, in the '90s, on hepatitis C or was
5 consideration given to those with chronic hepatitis B?

6 A. It was totally focused on hepatitis C. Again,
7 hepatitis B was known -- was a known issue amongst the
8 recipients of blood products, and had been for
9 decades. And -- however, my recollection is that it
10 wasn't, again, felt to be, you know, of the same order
11 of a problem as let alone HIV or hepatitis C.

12 Q. In relation to the hepatitis C litigation and the
13 legal advice, in your witness statement you've
14 discussed the legal advice that had been received by
15 the Society and by various legal firms, and you've
16 said that the advice received by those groups was in
17 many cases contradictory.

18 A. Mm-hm.

19 Q. What do you mean by that? What was contradictory?

20 A. There's a specific example, I think in 1986 [sic], in
21 The Bulletin where we actually had a piece by two
22 solicitors, firms representing people who were
23 litigating, which gave directly opposing views on the
24 prospects of success. So that is what I meant.

25 **SIR BRIAN LANGSTAFF:** Do you mean 1986?

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1 a key motivation of him making that policy, in
2 discussions I've had with him. And it was that
3 consistent failure over many years by governments of
4 varying different colours to implement that promise,
5 which, if implemented, might not have eliminated all
6 of the problems that we've had to deal with but would
7 have vastly mitigated those -- the number of people
8 infected and affected, by a considerable amount.

9 And so, consequently, we believed that the
10 Government on the day -- or all governments -- had
11 a moral responsibility to redress the failure to
12 implement that Government policy.

13 Q. And you've spoken about the campaigns that the Society
14 was running and you said there were competing demands
15 on resources of the Society. Could you just briefly
16 explain what those demands were?

17 A. Well, we still had ... we had -- during the 1980s, or
18 from when I was involved, 1985 through to the early
19 '90s in particular, you know, you had -- on the one
20 hand you had hysterical media coverage about HIV,
21 which seriously impacted virtually all of our members
22 in some way or another. Because, as I think I've
23 already mentioned, haemophilia became a marker for
24 HIV. And so you had people -- as I said, children who
25 were being discriminated against at school, people

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1 whose job prospects were being put under threat, their
2 homes were vandalised, and so we were dealing, as
3 a Society, with a flood of requests for help and
4 support coming in. So we had that.

5 We had the increasing call for campaigning,
6 something which the Society had not done previously,
7 and from -- had to get up to speed and learn new
8 tricks, as it were, in terms of campaigning from about
9 1985, 1986 onwards.

10 And at the same time we had to deal with what
11 I would describe as business as usual, which was
12 dealing with and supporting people, young families in
13 particular, with haemophilia, with children. And so
14 we had all of this happening at the same time with
15 a very small staff and volunteer trustees, and a very
16 limited financial income, as it were.

17 So those were some of the factors which were
18 competing at all times for attention and resources.

19 **MS FRASER BUTLIN:** I'm just going to check my ...

20 Sir, those are the questions.

21 **Question from SIR BRIAN LANGSTAFF**

22 **SIR BRIAN LANGSTAFF:** I have just got one question to ask.

23 I don't think I've ever, in my career yet, had
24 a case in which it has been known that one side has
25 said in an open document to the other side, "Our legal

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1 because they knew that it would take a long time and
2 might not succeed. And a lot of our stakeholders or
3 key people that we were dealing with, people like MPs,
4 when we were seeking their support, would say, "Well,
5 can you not go for redress in the courts?"

6 And so it was important to be able to explain to
7 them, but yes, we could go to the courts, however, as
8 you say, the prospects were uncertain, the advice that
9 we had had was that that might not succeed or if it
10 would succeed, again, it would not be in a timely
11 manner to help the people who were in urgent need.
12 And therefore, please Mr or Mrs MP, would you support
13 us with this moral or political campaign? I don't
14 know if that helps.

15 **SIR BRIAN LANGSTAFF:** Well, it does indeed. That's all I
16 ask. Thank you very much.

17 **MS FRASER BUTLIN:** Mr Taylor, is there anything else you
18 would like to add?

19 **A.** I've got a brief statement, if that's all right.

20 I just wanted to say, first of all, how much I welcome
21 this Inquiry, decades late, and too late for so many
22 friends and colleagues. But I really very much
23 welcome this Inquiry.

24 It's in the nature of an Inquiry such as this
25 that it focuses on what went wrong. But we must not

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1 advice says we're going to fail".

2 Why was it that the Society said that they had
3 had advice, ie legal advice, to that effect, rather
4 than simply saying -- because the point is the same --
5 there were various difficulties in the way of pursuing
6 a legal case? You didn't need to enumerate them, they
7 might have been obvious at the time, in the law as it
8 was at the time.

9 But would that not have done the job, to
10 simply -- why is it necessary to mention the fact that
11 you'd had a legal advice as opposed to you appreciated
12 there were various difficulties in the path -- you
13 might overcome them, you might not, but there were
14 difficulties in the path of pursuing compensation?

15 **A.** I think there are two things. One is I think that,
16 first of all, the fact that we had had legal advice
17 was in the public domain, because we had told our
18 members that asked us to get legal advice, we sought
19 legal advice and we told our members what the legal
20 advice was. So, first of all, it was already in the
21 public domain.

22 I think the second point is that, as I think
23 I may -- I said earlier, was we believe that the
24 Government felt that, for them, trying to push us into
25 pursuing a legal option was for them the easy way out,

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1 forget the huge amount of good that the Society did
2 during this really very, very difficult time,
3 supporting our members and campaigning on behalf of
4 our community.

5 The trustees were all volunteers from the
6 haemophilia community, in many cases were individuals
7 who were ill with or dying from HIV or hepatitis C,
8 whilst they still campaigned for those infected and
9 affected. The background public climate of stigma and
10 fear towards HIV in the 1980s and '90s placed huge
11 additional pressures on the Society, its trustees and
12 all of us publicly campaigning on behalf of people
13 with haemophilia.

14 The external environment, as I have said, was
15 extremely fearful and hostile to anyone with HIV or
16 AIDS. Having haemophilia became a marker for AIDS and
17 we have members who lost their jobs, children
18 stigmatised at school, families whose homes were
19 vandalised. The staff of the Society, particularly
20 David Watters, moved mountains to help in individual
21 cases such as these.

22 HIV and hepatitis C were new and emerging
23 threats that were poorly understood for many years,
24 particularly in the case of hepatitis C. As is
25 frequently the case with emerging threats, the

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1 scientific and medical advice was frequently
 2 confusing, conflicting, incomplete and, with
 3 hindsight, some of it was incorrect.
 4 But I'd like to believe that we always acted in
 5 the utmost good faith.
 6 The Society and the great majority of our
 7 members did not believe that, for the most part,
 8 haemophilia clinicians were negligent. Time and time
 9 again, we were told that individuals did not want to
 10 take legal action against their doctors.
 11 By and large haemophilia clinicians cared deeply
 12 about their patients and acted in good faith in their
 13 treatment. Accordingly, the focus for Society's
 14 campaigns was always to persuade Government to meet
 15 its moral responsibility for its negligent behaviour.
 16 I, and the Society, have always been convinced
 17 that the root cause of the disaster, and in particular
 18 its scale, were the inherently unsafe practices and
 19 processes connected with paid blood and plasma
 20 collection in the US and elsewhere in the 1970s. It
 21 was a risk recognised by the UK Government, and by
 22 Dr David Owen as Health Minister when he made the
 23 commitment to UK self-sufficiency in 1975.
 24 It was then the failure of successive UK
 25 Governments to implement this commitment that led to

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1 died.
 2 I would contend that for such a small charity,
 3 whilst the outcomes of our campaigns remain
 4 unfulfilled to this day, what was achieved was truly
 5 remarkable and is a testament to the staff and
 6 volunteers involved, and my thanks goes to all those
 7 over the years who have kept this issue alive. Thank
 8 you.
 9 **SIR BRIAN LANGSTAFF:** Thank you very much. You have
 10 filled in some of the gaps for us, that we had, in
 11 particular evidence covering the campaign which The
 12 Haemophilia Society ran successfully for getting some
 13 money, at any rate, out of the Government, the story
 14 of the birth of the campaign, in respect of
 15 hepatitis C, and generally you've illuminated other
 16 evidence we have already heard, but you've illuminated
 17 it further in respect of the Macfarlane Trust.
 18 So I would just like to thank you for giving the
 19 clear evidence you have. Despite what you said at the
 20 start would be a gap in your memory in the 1990s, it
 21 doesn't seem to have affected you very much and I'm
 22 very pleased about that. So thank you.
 23 **A.** Thank you.
 24 **SIR BRIAN LANGSTAFF:** Tomorrow.
 25 **MS FRASER BUTLIN:** Tomorrow the Inquiry will hear from

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1 the prolonged reliance on imported blood products,
 2 that in turn infected so many of us with HIV and
 3 hepatitis C.
 4 Whilst much of a focus of the Inquiry to date
 5 has been on the actions of medical professionals, and
 6 now on the Society and other campaigners in due
 7 course, I believe that most of us whose lives were
 8 devastated will be focusing on the evidence from
 9 Government that is yet to come, as to why
 10 self-sufficiency was not introduced when it had been
 11 promised, and why they were content to place the
 12 safety of British lives in the hands of foreign
 13 companies who had a proven record of playing fast and
 14 loose with product safety.
 15 Individuals on the Trustee Board itself were
 16 living under the personal pressures of living with
 17 haemophilia, HIV and hepatitis. No one could
 18 seriously suggest that the trustees were not taking
 19 the issue seriously when so many of our own members
 20 were infected and we were working alongside friends
 21 and colleagues who we watched become ill and die,
 22 knowing that this same fate awaited ourselves.
 23 During my time on the Executive Committee, at
 24 least six of my trustee colleagues died from HIV. And
 25 personally, another six of my friends from school also

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1 Ms Karin Pappenheim. I think she will be remote.
 2 **SIR BRIAN LANGSTAFF:** She will be remote. So tomorrow
 3 10 o'clock, to be heard remotely, obviously screened
 4 here for those who are here.

(2.33 pm)

(Adjourned until 10.00 am the following day)

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(43) you've... - yourself

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