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.

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?

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?

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.

A. Mm.

Q. Do you recall either you receiving them or hearing about them from your mother?

A. Um, yes, but not in a major way. I wouldn't say they were a major source of information to me. The major sources of information to me were what I was reading in the press, more than anything else at that point, before I joined -- before I became a trustee.

Q. In your statement, you've said that many people with haemophilia were isolated, and that often GPs, dentists and other health professionals were frequently unequipped and often unwilling to provide appropriate help and support, and some people with haemophilia were treated by well meaning but inexpert haematology consultants with very small cohorts of haemophilia patients?

A. That's correct.

Q. And you say that the Society played a crucial role in addressing some of those problems?

A. That's right. Yes.

Q. Was that in part by providing information to patients so that they knew what treatment they could expect and perhaps what the risks of treatment were?

A. Absolutely. So one of the core functions of the Society at that time, and I would probably consider

probably even to this day, was to enable and empower people with haemophilia, so that they could know what to expect from their medical and clinical professionals and also to provide help and support if they weren't getting it. So one of the things that the Society did was to sometimes intervene on behalf of patients, as it were, to help them if they had a difficulty with a GP or a dentist or something like that.

Q. So in terms of the information being provided by the Society, to their members, what it was your sense of how much people were relying on that information? What weight they were putting on that information?

A. I would think not a lot is the short answer. It would be informative but the primary relationship was always with the treating physician. And because of the nature of haemophilia, I believe that people with haemophilia tended to have very close relationships with their Centre Director and their Haemophilia Centre, and whilst it was information, I am not sure or not convinced that people necessarily relied on it. But it was to inform the conversation that they would then have with their doctor.

Q. So there was no sense at all of the Society trying to replace the role of the doctor providing advice?

A. Absolutely not. We were all lay individuals. We had, for the most part, no scientific or medical training.

Q. But, as a matter of fact, would it be fair to suggest that patients may have relied on the information to some degree?

A. Yes. You know, obviously one can't speak for individuals, other individuals.

Q. But that was your sense, both as a member and in that early period of --

A. Yes.

Q. -- joining the Committee?

A. Yes.

Q. Could we have the document HCDO0000276_033, please. We can see this is the annual report of 1986. If we can turn to page 7, please, Soumik, and the second paragraph down, we can see that there's discussion of AIDS being the dominant theme of the last annual report, and reference in this paragraph to the attention given to AIDS by national newspapers. Then in the last sentence of that paragraph, it says:

"A main responsibility of the Society has been in seeing that errors of fact are corrected and accurate information made available speedily to our members."

Would it be fair to say that in 1986, the

Society was seeking to be an authoritative voice on AIDS and haemophilia to both the members of the Society and the wider public?

A. Yes, I think that would be fair. As the article points out, it was a time of alarmist media coverage, and we would send things out to try and explain, to reassure people that they couldn't pick up HIV or AIDS from, you know, sitting in a chair, for example, with somebody else, and that kind of -- those kinds of things. Because there actually also -- I think it might be helpful -- there were very few others at that stage, the Terrence Higgins Trust the National AIDS Trust, those were very nascent at that point.

Q. So there was a sense of the Society needing to fill a gap?

A. Yes.

Q. Could we then move forward to 1991, WITN4500002. We pick up the 1991 Bulletin, the fourth Bulletin in 1991 talking about "The Essentials of Haemophilia Care", and the launch of the new blueprint. The article starts by discussing the NHS reforms, providing an opportunity to set out a detailed standard for the care of all people with haemophilia in the UK.

We can read on, and it says:

"This care is normally provided at present by hospitals in health districts outside that where the individual lives, and so it has been necessary to explain to District Health Authorities ... what they should be buying and where that care should be provided."

Then the next column:

"The Society's document, 'The Essentials of Haemophilia Care' has been produced in order to assist DHAs in their new task ..."

The paper goes on to give guidance on how DHAs should go about -- and it's the next column -- contracting for these services.

So again, would it be fair to suggest that the Society in this example was seeking to be an authoritative voice in relation to haemophilia care and to educate District Health Authorities on what the Society believed to be the best treatment options?

A. Yes, that would have been produced in conjunction with the Haemophilia Centre Directors Organisation, who of course were the medical and clinical specialists. But the objective was to, as you say, make sure that District Health Authorities knew what they should be doing from a commissioning point of view and also again what patients should be able to expect from

their treating physicians.

Q. In your experience of being on the Executive Committee, the Trustee Board as it became later, was that something that carried on throughout your time, of being -- seeking to be an authoritative voice both for the members and for health bodies and for society generally?

A. Yes. You know, one of our -- as a health charity, one of our key roles was to advocate on behalf of our community in order to achieve the best possible standards of care, the latest forms of treatment, those kinds of things. And sometimes -- I'm sure we'll talk about it later -- you know, that came into conflict over cost issues and things like that.

Q. In terms of the mechanics of producing publications for members, so The Bulletin that we've just looked at and the Haemofacts that we've spoken of, we've heard in other evidence that the Executive Committee had very little involvement in what was put in them. Is that your recollection as well?

A. It varied considerably. So it might well be that a small group of the executive assisted with drafting elements of it, but they would also work very closely with specific clinicians. So if a document had a specific remit then we would turn to clinicians who

were expert in that particular area for advice. You know, but ultimately, then the editor of The Bulletin would work with the -- David Watters and the chairman probably in the final copy, as it were.

Q. Could we have HSOC0019583, please. We have here a Bulletin from 1988. And it's the very first article, thanks being recorded for Clive Knight's lengthy time as editor of The Bulletin and other publications.

In the second-to-last paragraph we see that it's noted he's:

"... continuing to serve on the Publications and External Relations Working Party so his experience and expertise will not be lost."

Were you also on that committee, that working party?

A. Quite possibly. I don't recall directly, but it is quite possible, yes.

Q. And can you tell us anything of what involvement that working party had in the production of The Bulletin? Or other publications?

A. I don't recall specifically. Again, we might have acted as sort of subeditors or contribute individual articles but I don't recall particularly.

Q. Is it right, then, that the editor, the chairman and

the coordinator were primarily deciding what articles would be produced, but there might have been some assistance from some Executive Committee members?

A. I think that's right. I think the editor would have done most of the heavy lifting, as it were, in terms of writing it. But suggestions from articles would have come from other executive members, from local groups. Individual members, even, would have contributed articles or made suggestions as to content, as it were.

Q. And when that content was clinical --

A. Yes?

Q. -- you said it would have come from a clinician?

A. Well, again, it varied enormously. So sometimes it would have come from a -- directly from a clinician, and there are many examples in the evidence of articles by clinicians. If it was a more general article, it might then be written by somebody else on the Executive Committee and then run by a clinician to be checked.

Q. If an article was originally written by a clinician, was there any checking of it by another clinician or any form of double checking it?

A. No, not that I can recall. Sometimes there would be a sort of consensus view. You know, if it was a particularly important piece, a number of clinicians might be asked for their input and contribution.

Q. And how would one know that from something one was reading in The Bulletin?

A. Probably credit would have been given.

Q. So if it's authored by one doctor, would it be fair that that article has probably been written by them and not checked by anyone else?

A. Probably.

Q. But if it's written perhaps by an Executive Committee member but credit is given to these number of doctors, it's probably that there's been an input from those doctors to form a consensus view?

A. I don't recall directly but I think it highly likely.

Q. With that input from the clinicians in medical articles, was that primarily from the Medical Advisory Panel?

A. No, not necessarily. It's -- they were quite often the first port of call. But again, there may well be clinicians who weren't -- didn't happen to be on the Medical Advisory Panel who we knew to have a particular interest or expertise in a particular area. So it would almost all -- it would pretty well always be a Centre Director of a Haemophilia Centre. Occasionally it might be a pure specialist, but it would always be at least a Centre Director.

Q. In your statement, you're clear that the Medical Advisory Panel was an advisory panel?

A. Mm.

Q. And that the Society would make its own policy and decision as it felt fit. Was that the position throughout your time on the Committee or did the Society's interaction and approach with the panel change over time?

A. I draw a distinction between what I would call medical and scientific information, where we weren't competent to second-guess the Medical Advisory Panel, and issues relating, for example, to policy on some aspects of treatment. So, for example, in the 1990s, as what became known as high-purity Factor VIII products came in, and then in due course recombinant artificial products, which we use now, came in, we were much more aggressive in calling for their introduction than the Medical Advisory Panel or the Haemophilia Centre Directors organisation were. So one might see, as I say, a slight disconnect in an area like that, but as far as sort of clinical -- sorry, in scientific terms, then, you know, we weren't in a position to, as I say, second-guess them.

Q. We're going to come on to the review of the Medical Advisory Panel that took place in 1991 in just a moment, but in relation to the period before 1991 I think you've said that you had no direct dealings with the panel at all during your tenure?

A. Not officially. I knew some of them personally or acquaintances with them but not officially. Relationships were usually between the chairman or the general secretary or with the staff, particularly. So either David Watters or, in due course, Graham Barker. They would have had the direct contact with them.

Q. So can you help us with this: if the Executive Committee felt they needed advice on a particular issue, how did that reach the Medical Advisory Panel?

A. That would be delegated to probably David Watters or Graham Barker, who was the policy manager, and they would seek advice from the Medical Advisory Panel.

Q. And then how was the advice conveyed back to the Committee? Did you ever get anything in writing from the clinicians or was it --

A. Yes.

Q. -- primarily verbal?

A. Again, it varied enormously depending on the nature. So, again, I'm sure we'll cover it, but, you know, we would get feedback at executive meetings or policy and group meetings or whatever. But it would probably be mostly verbal.

Q. I'd just like to unpick a little more about the clinical information that was in some of the Society's publications, and you've addressed the situation for patients in some detail in your witness statement. Could we put that up on the screen so everyone can see what we're looking at. It's WITN4500001 and it's paragraphs 22 and 23 to start with.

Page 5, Soumik.

Here in paragraph 21 you've talked about:

"Responding to the HIV impact on the haemophilia community created a huge range of tasks ..."

And then paragraph 22 and 23:

"Initially the most urgent need from the community was for information on the threat, and support and advocacy in responding to it."

23:

"Reliable information was difficult to obtain, both because it was a new and emerging threat about which little was known, but also in the early days there had been differences in opinion by clinicians as to the impact on people with haemophilia."

Could you expand on that for us, please? You say there were differences in opinion. What are you addressing there?

A. I think it's an issue which I think the Inquiry has looked at previously, in that there were -- and this is slightly in retrospect, because the -- as I say, I wasn't around in 1983/84, around about that period, but there was -- appeared to me to be -- have been a difference of opinion between some clinicians as to whether or not HIV was a serious threat to people with haemophilia or whether it was something that was going to be confined to the gay and drug use community. And also, there were issues about whether or not there were -- because of the high level of treatment that we'd had, whether that was going to impact. So there was -- it was my perception that there were some -- there had been some differences of opinion.

Q. And was that perception formed when you joined the Society more substantially in 1985/86 or is this a hindsight reflection?

A. I think it was -- no, I think it was around about that time, because there was -- there was a lot of confusion. There was a lot of uncertainty around the whole issue of HIV. There was uncertainty about its -- elements of its transmission and I just remember that there was a lot of areas of uncertainty. I can't remember detail.

Q. Were there discussions, then, within the

Executive Committee meeting, or perhaps as the side conversations over coffee afterwards, about those difficulties?

A. Not particularly. I think the issue that really I'm referring to there is actually probably in the -- you know, the earlier paragraph, 22, you know, was core information about how -- dealing with HIV. And that was the key issue. So people needed to know, you know, were other family members at risk? There was a whole area about, as I say, transmission. And it was those areas particularly I think that we were concentrating on.

Q. Were you aware of any discussions that reflected back on the advice that the Society had given in '83?

A. No.

Q. This was primarily about what was happening in '85?

A. Yes.

Q. You also say here that reliable information was difficult to obtain. Can you give us anything more specific on what you're dealing with here?

A. Again, this is just dealing with HIV specifically as an issue. I can't recall exactly, even though I was later very involved in Terrence Higgins Trust, when that started up. I think it was '94, '95. But again, they only had one member of staff. There was a real

shortage of information from reliable sources, and indeed, as a result of that, I and -- I haven't mentioned it, but I and others from Terrence Higgins Trust sought to set up the National AIDS Trust to provide an authoritative source of information. You know, there was information from doctors, but there was no -- at that point, very many organisations who were saying, you know, "You don't have to worry about sharing your seat with somebody who has got HIV, you don't have to worry about being in the same room as them, you don't" -- and we were dealing with a whole range of issues, which again, clear in the evidence, of children being discriminated against at school, of people who, you know, were not getting medical treatment because of their HIV status.

And that was the focus of our activities around about that time, was trying to address and deal with situations like that.

Q. I don't want to put words in your mouth --

A. No, I'm sure.

Q. -- but it sounds like you're describing quite a vacuum of information.

A. Yes, it was a huge vacuum.

Q. Paragraph 25 of your statement indicates that from your perspective the response to these issues was

a need for regular and rapid communication of information --

A. Yes.

Q. -- from a trusted and independent source?

A. Yes.

Q. So would it be fair to suggest that the Society was seeking to fill that vacuum --

A. Yes.

Q. -- with information?

A. Yes.

Q. Would it also be fair, therefore, to suggest that, by filling that vacuum, that they were anticipating that people would rely on the information they were being provided with?

A. You give people information, it's for them to deal with it. But, you know, we hoped they would. Particularly, as I say, in response to HIV at that point.

Q. How much of this information that you were providing was coming from the Medical Advisory Panel, was coming from clinicians?

A. It would all have been coming from clinicians. We would have been, sort of, interpreting it, and turning it into lay language which was accessible to people. So I mentioned there, for example, Dr Peter Jones who played a leading role in supporting us at that point, and the publication that he is referred to there, AIDS and the Blood. It was a very important document which, in lay terms but in the context of haemophilia, was made available to members so that they could understand, as we knew it in 1985, you know, what having HIV meant for them.

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

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

Q. '85, '86, I think.

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

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

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

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

I'm sorry, Soumik, my fault. HSOC0010277. We're picking up a document in relation to the Medical Advisory Panel review in 1991. Paragraphs 2 and 3 are what I want to look at:

"The starting point for this review was the concern felt by Society representatives attending MAP that some of the meetings were not a productive use of their time. There was a feeling that on occasions both the Medical and Society members of the Panel felt disappointed with the substantive outcomes from the meeting. This raised the question as to whether there was possibly no need to have regular meetings or even

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

Then paragraph 3:

"It was agreed that the Society needs advice and information on the latest medical and scientific developments in the fields of both treatment and research. This advice is needed on both an informal and formal level.

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

Now, before I ask you in detail about that document you've actually already addressed it -- you've already addressed it in your witness statement. Again, it may be useful to have the paragraph on screen so we can all see it. It's paragraph 71 of the statement, WITN4500001, page number 14, paragraph 71. You've said here:

"There was a belief by the Society that it desperately needed independent, unbiased, expert medical and scientific advice on the huge issues

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

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

A. It was ongoing over a period of time, and I noted from the date of the earlier document that I probably wasn't actually a trustee at that point. However, I think there was certainly a sort of conflation between the role of the Medical Advisory Panel, and the Haemophilia Centre Directors Organisation, and I think that, as I say in my statement, that we weren't necessarily convinced that we were getting from MAP as a body, necessarily the most helpful information.

We would get it usually from an individual who might be a member of the Medical Advisory Panel, but I think, as a group, it wasn't at that point, I think, terribly good at sort of coming to a consensus view, and I think they were influenced by other factors, which was one of the reasons why we had the review at that point, and we changed the structure, to some extent, of the Medical Advisory Panel, and I think made a clearer distinction between the HCDO as the Centre Directors running Haemophilia Centres, and the medical panel.

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

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

Q. What do you mean by that?

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

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

A. Yes.

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

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

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

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

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

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

A. Yes.

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

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

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

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

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

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

A. Indeed.

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

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

But it was -- I'm reflecting there a sense that I think I and other members of the Executive had.

SIR BRIAN LANGSTAFF: Yes, it was really just the combination of covering their backs by doing something. I can understand covering backs and taking an overly conservative view, but ask ...

A. Maybe I was a little sloppy in my writing.

SIR BRIAN LANGSTAFF: No, it's your writing and I'm just trying to understand it.

A. No, I think it was -- as I say, I think it was -- we had a number of different things going on at the same time. So in some cases they would not want to break the consensus view. In other cases they might take a more conservative approach than we would take, because we would feel on the frontline of emerging threats. And, you know, it's possible we would come out of an interaction with them thinking: well, are they taking this seriously enough? And sometimes being conservative is a way of, you know, not raising your head above the parapet and, as I say, taking the easy approach. I don't know if that helps.

SIR BRIAN LANGSTAFF: No, that's quite helpful. Thank you.

A. Thank you.

MS FRASER BUTLIN: I want to move on now to the HIV campaign.

A. Mm-hm.

Q. What was the Society campaigning for when you joined in 1985? What status was the campaign at at the point that you joined?

A. There wasn't really a campaign when I joined. And indeed, one of the reasons I joined was particularly for that very reason: you know, professionally, my professional experience was in communications, public relations, political lobbying, and one of the reasons I came forward was because I felt that that could be helpful to the Society. And I think at that point there wasn't really -- it was still a question of coming to terms with this amazing -- this awful, dreadful thing that had happened. And so it was probably opportune time for me to get involved, to help develop, start develop campaigning.

Q. Just in terms of how you got involved, did someone come and talk to you and say, "Look, we'd love to have you", or was there something in The Bulletin that you looked at and thought: gosh, I could be really helpful? As an ordinary member, how did you make that transition onto the Committee?

A. I got in touch with the general secretary, David Watters, and said, "Hello, here I am". Because I hadn't had any interaction with them, I didn't know them, they didn't know me particularly, or know that I existed, and so I made myself known to them and said, you know, "Can I help?"

Q. So how would other members of the Society have been able to influence what the campaign would be or how the campaign would be run? Was there any opportunity for members to shape it?

A. Yes. There were interactions. So, for example, the annual meeting, council meetings which were held, I believe if I recall, twice a year, you know, which was when sort of ordinary members, if we could use that term, and representatives of groups would meet with the Executive Committee. So they'd have an opportunity at that point. But I think, also, an awful lot of members were in touch with the Society on a sort of -- through correspondence and telephone calls. Apart from asking for information and help, I think they would have been saying, you know, we need to do something about this.

Q. You also say in your state that the Committee was informed by political, legal, and the medical advice given on a personal basis, ie, outside the formal structure of the MAP, the Medical Advisory Panel, in relation to the campaign.

What medical advice did the Committee receive in relation to the campaign?

A. I particularly -- thinking there, again, of the work that Peter Jones did in producing supporting materials that were used in the campaign. And again, there were documents in the evidence of what the impact was on people with haemophilia. So -- which we could then use with opinion formers for media, politicians, people like that.

Q. Did clinicians have any role in saying what the Society should campaign for?

A. No.

Q. Could we turn to HSOC0023211, please, Soumik.

We have here an agency brief that you wrote together with David Watters in February 1987. And if we turn to page 2, we can see under the heading "Legal Remedy" where it's said:

"A limited number of legal actions have been started in the United States against commercial manufacturers of blood products. Those cases are not supported by the National Haemophilia Foundation (the US equivalent of the UK Haemophilia Society) as it is envisaged that this could bring about problems with the supply of concentrates in the United States. Indeed, the concern is that the manufacturers might withdraw from the production altogether. While it is the case that in the UK the Central Blood Laboratories Authority produce a considerable amount of concentrates under the National Health Service, this amounts to any (currently) 22% of the UK requirement."

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

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

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

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

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

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

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

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

A. No.

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

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

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

A. Mm-hm.

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

A. Mm-hm.

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

A. Yeah.

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

A. Yes, yes.

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

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

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

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

Q. The paragraph then goes on to say that:

"... [the Society] has been advised that claims for compensation as such are most unlikely to succeed because of the difficulty of proving negligence. In any case, the Society is advised that any solution which may be provided by the courts will not be available in the short term. However, the needs of families are immediate."

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

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

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

Q. It could be suggested that by telling the Government "We don't have a legal case", that the legal advice is negative, that was strengthening their hand in any negotiations because there wasn't the threat of litigation behind it. What would your response to that be? Was that something you discussed and thought about?

A. I don't recall specifically whether or not we discussed it but, I would say, the -- it was really important, because they wanted us to go to court because they knew that it would take years, it would be very difficult to prove, and we had to say that, as I say, they were being disingenuous in suggesting this. And we had to say it, not just -- this was not a submission just to Government, this was a submission and a briefing to our politicians of all parties. And in order to build a consensus, a coalition, rather, of support, it was important to say the Government have said this the route we should go down, it's a false route, and that we need help now and there is a political and moral argument that they should meet.

Q. There were some members of the Society who were litigating?

A. Absolutely.

Q. Was there any consideration given to whether this would undermine their position in the litigation?

A. I think the view was that it wouldn't really make any difference because the law would be what the law was. This was a political campaign and, as became clear after 1987, the two ran in parallel, effectively. So

we had the litigation actions taking place but we also had the political media and moral campaign going on at the same time. So we were effectively attacking from both sides.

Q. This was in October 1987.

A. Yes.

Q. It was really quite a short campaign in the autumn --

A. Yes.

Q. -- because on 16 November 1987, as we know, the fund of £10 million was announced?

A. Indeed.

Q. After the money was announced to set up what became the Macfarlane Trust, you've described that there was then to be a second stage of campaigning --

A. Mm.

Q. -- for further monies.

A. Mm.

Q. Is that right?

A. Yes.

Q. Could we turn to HCDO0000276_043, please, Soumik. We can see the headline of The Bulletin, it's the fourth Bulletin of 1987 "It's a start", and as we go through the article, we can see that there's three points that are made:

"Firstly, the justice of the Society's call for

recompense has been acknowledged."

Then further down the next paragraph:

"Secondly, the allocation of £10 million from the Treasury to meet some of the financial needs of those affected is a timely, flexible and compassionate gesture from the Government."

Then the next paragraph:

"Thirdly, the fact that the fund has been given into the control of The Haemophilia Society to administer is attribute to the esteem in which the Society is held by the public and the Government."

The article carries on to the final page of The Bulletin which we don't particularly need to go to, but there's nothing in the article that sets out what will happen next with the campaign, at this point.

A. No.

Q. Had there been any discussions at that stage --

A. Um --

Q. -- about what we're --

A. Not that -- you know, we're talking about a really short period of time. We're talking about, you know, a few weeks. And our focus was very much on, you know, how do we now -- how do we now respond? I think that a few months later, then we started thinking about the next stage.

Q. Let's look at that together. HSOC --

A. Sorry, could I just add?

Q. Of course.

A. The phrase "It's a start" implied that from day one we recognised that this was going to be insufficient, and it was. It was a totally insufficient and inadequate amount of money. But it was a foot in the door. It was a recognition of the moral case that we had put, and that we would be back for more.

Q. And that's what I want to pick up with you, Mr Taylor.

A. Okay.

Q. If we can turn to HSOC0019910.

It's dated 14 December 1987, so very quickly after the announcement. It's the Haemofact 17, "The Campaign Continues", and if we go to the last page of the document, page 4, I think -- that's it -- we can see the three points that the campaign is going to be focused on:

"The continuing need for a special weekly benefit.

"The need to speed up DHSS procedures for dealing with claims for Attendance Allowance and other Social Security benefits."

And thirdly:

"The importance of provision for life insurance and mortgage protection."

And then the note:

"In future, the Government has left the door open for us to approach them if it becomes apparent that our needs have not been met. We are confident that in further representations to the Secretary of State we shall receive the same consideration as at our earlier meeting."

Is it fair to say that at this point in time the Society was not immediately saying, "We need more money", but the understanding was that if it was needed then it would be forthcoming?

A. We weren't -- it wasn't guaranteed. And we didn't really know. I think we might have been seeking to put words in the minister's mouth, shall we say, by saying that they would -- you know, they would come back with more. And the campaign, and the requirements of the campaign, developed a bit more over time, as we had more time. But as I say, you know, in November and December of 1987, there was -- we were sort of overwhelmed with an awful lot of logistical issues, just dealing with literally -- you know, I remember the general secretary receiving a cheque, and thinking: what do I do with a cheque for £10 million? So it was quite nuts and boltsy at that stage, as well as dealing with our members, who were saying "Well, when am I going to get my money?" kind of thing.

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

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

A. Well, I wasn't directly involved in the discussions and I hadn't been involved in the discussion with the Secretary of State, so I wasn't in a position to say that. But I think -- I think we were expressing, as I say, a strong hope, and we were expressing -- we might be putting an interpretation on it, as I say, partly to put more pressure on the Government, to say, "You have said" -- in the future to say, you know, "You have said that, you know, there might more money available."

Q. As you say, you were a trustee of the Macfarlane Trust from 1988 to 1990?

A. Mm-hm.

Q. In your statement you've said you felt you had to balance the desire to be generous with the need to preserve the capital of the fund.

A. Yes.

Q. Why did you consider that the capital of the fund had to be preserved?

A. Because we hadn't had a firm assurance that more money would be made available. And that wasn't made available -- that wasn't made, I believe, until a meeting, as I say, I think two years later, where the Government said, "Yes, we will provide additional funds". So we had to take, to some extent, a precautionary approach with the capital.

Q. But by taking a precautionary approach, did that not perhaps mean that the Government wouldn't realise that there was greater need? Was there any discussion about that?

A. No. Well, I think the -- again, we had to make a balance, as I think I said, between being sort of -- showing the Government that we were being responsible custodians and therefore worthy of more money, whilst at the same time the Society keeping the political pressure up, that additional funds should be made available.

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

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

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

A. No, we were independent. We made our own decisions. But as I say, we weren't certain at that point, for the first year or two, whether additional funding would be made available. And so we, as I say, had to balance generosity with -- with, you know, if we don't get any more money, then we need to make sure that there is funds ongoing for some considerable time. We couldn't guarantee it until, as I say, that other meeting in 1989 where I believe the minister agreed that there would be additional funding. That changed the situation for the Macfarlane Trust and we then realised that additional regular funding would probably become available and that could change the situation and the way that the Trust worked.

Q. In seeking to ensure that the Government was content with how the Trust was operating, was the Trust then constrained in what it did?

A. I wouldn't say that, but it was important that we were being seen to act responsibly, you know, with proper procedures, that kind of thing, is really what I'm -- I think we're getting at.

Q. Did it impact on that decision about how generous the Trust could be?

A. Well, we could have just given away all the money, but if -- as I say, without a guarantee of additional funds then that would not necessarily have been in the best interests of the beneficiaries, if we'd sort of blown the cash, as it were.

Q. You spoke a moment ago about the Macfarlane Trust administering the money --

A. Yes.

Q. -- and the Society putting the pressure on the Government to increase the funding.

A. Mm.

Q. In relation to the Society, with the benefit of hindsight, do you think they did enough to press for more financial support in relation to the Macfarlane Trust?

A. I would think yes, because the money came. We got the money. Which is the bottom line.

Q. Do you think they could have done more to get it more quickly?

A. Political campaigns are uncertain. I think that a two-year period, the Government wasn't going -- I don't think the Government was going to come back more quickly than, as I say, a two-year period. They've said well, you know, "We've given you £10 million, get on with that", as it were. So I think it would have been highly unlikely that the Government would have moved any more quickly, regardless of what the Society or anybody else had done.

Q. I just want to explore one further aspect in relation to the Society. Could you turn with me to -- sorry, Soumik could we have HCDO0000279_004, please. I'd just like to go to page 2, please. This is a bulletin, the first Bulletin of 1989 and we can see in the first two paragraphs, it says:

"The Editorial Board has recently been considering the extent to which matters relating HIV and AIDS should feature in the Bulletin and Update. Some readers have suggested that these topics receive too much attention in these pages.

"Since the advent of AIDS, the Haemophilia Society as a whole has made strenuous efforts to maintain a 'One Society' approach for people with haemophilia -- with and without HIV."

It goes on to discuss what they're going to do about publications. First of all, can you tell us how the Society came to hear those comments from members, how was the Society aware of those different concerns?

A. I would guess that that would have been through telephone calls, correspondence to the office and to the officers. So that would have been to the chairman and to David Watters, people -- there were a lot of people, a lot of our members, who either because they were not directly affected by HIV or, indeed, if they were affected, found the coverage in the Society's publications what we would now call triggering, and were -- felt that, as I say, as the article -- as the editorial says, that we were placing too much emphasis on it.

I think it's particularly true of cases of -- we had a lot of -- the Society particularly has always

catered for families with young children with haemophilia and because of the nature of the condition, if you have a child with haemophilia, particularly if it's not been in the family, you know, then the family want help and support. And so I think there was a feeling that lots of talk about HIV and things like that was not necessarily family friendly. So -- but as I say, there was some pushback but we felt that we should keep the balance and, you know, we had a duty to cover these sorts of issues.

Q. This is obviously talking about the publications?

A. Yes.

Q. Had there also been some pushback about the campaign that had been run?

A. Yes, indeed. And the -- there were, you know, elements of the membership who felt that the whole high profile that -- or the connection that haemophilia had with HIV was unhelpful, because again, as I've said elsewhere in my statement, haemophilia became, in the public perception, a marker for having HIV or AIDS. And so people who had haemophilia were finding themselves subject to discrimination and stigma. Just for having haemophilia. Let alone having HIV or AIDS.

And so there were -- you know, there were quite a few people who felt that they didn't want that high profile. And this happened again in years to come over hepatitis as well. You know, they wanted to just quietly get on with their lives of having haemophilia.

Q. That's one side of the spectrum. Were there others at the other end of the spectrum who were seeking greater campaigning work from the Society? In relation to HIV; we'll come to hepatitis later.

A. Um, yes. And we had that constant balancing act between people with HIV who felt that we should be doing much more, and people who did not have HIV who felt that we were already doing too much. And as trustees, we had to balance those, and one never completely succeeds.

MS FRASER BUTLIN: Sir, I'm about to move on to a different topic and I see the time. I wonder whether now is a good time to take the morning break.

SIR BRIAN LANGSTAFF: Yes, it is. We'll take a break until quarter to 12.

Now, Mr Watters [sic], you may have been watching previous sessions, you will know that on each occasion that there's a break, a first break anyway, I advise the witnesses that at any break they must not discuss the evidence they have given, or may yet be asked to give, whatever else they wish to talk about.

THE WITNESS: Indeed. Thank you.

SIR BRIAN LANGSTAFF: Quarter to 12.

(11.15 am)

(A short break)

(11.46 am)

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: I want to turn to the hepatitis project team that was set up in September 1991.

Could we have HSOC0003297, please, Soumik.

This is an internal memo dated 30 October 1991, indicating that:

"At the first meeting to the project team I agreed to write to [Professor] Preston, Dr Hay, Dr Lee and Dr Mayne to test out the ideas we generated at our meeting."

Then if we go over the page we have the letter that was sent out, and it's dated 23 September 1991.

We can see that this letter has gone to Dr Hay, and it says that:

"The Society is beginning to look at the question of hepatitis and haemophilia. As a first stage we have set up a project team to identify possible areas of action and I am writing to you to seek your comments and views on our initial ideas."

So it appears from these documents that September 1991 was when the Executive Committee started to engage more substantially with the question of non-A, non-B hepatitis and its possible long term consequences. Would that accord with your recollection of that time?

A. I can't really comment, except that clearly we did, because I was not a trustee until -- I rejoined the board in June 1991 so I'm not aware if there were any discussions prior to that.

But clearly the evidence shows that that's when we started looking at the issue --

Q. More substantially?

A. -- more substantially.

Q. Do you know what had caused the Society at that point in time to consider the issue more substantially?

A. No. Um, no.

Q. The letter to Dr Hay then sets out a series of questions. It reads:

"Our starting point was the need to have some basic information on the scale and nature of the problem. Are we right in thinking, for example, that most (how many?) older patients with severe haemophilia have been in infected with hepatitis C at some time in the past? Are we right in thinking that in most cases this is not a problem and that in only a small proportion (15%?) of cases would this result in cirrhosis of the liver, causing death in a few cases. What are the medical problems facing the majority? We want to be able to reassure our members with some simple clear factual statements. We would, in particular like to be able to reassure parents with children under a certain age, that provided they have only received certain blood products they are not at risk of hepatitis. Can we reassure others that although they may have hepatitis they do not require any treatment and that there is little for them to worry about?"

How had the project team come to that preliminary view with percentages and an initial view of the seriousness of hepatitis?

A. I don't recall. Probably because -- as a result of conversations with clinicians.

Q. If we go over the page we can see in the middle of the page:

"On the question of treatment is there anything we can do in terms of promoting certain life styles or habits that might minimise the development of chronic liver disease? Are there certain things that people with hepatitis should not do or avoid?"

The fact that the question is being asked in this letter in September 1991 might suggest that the Society hadn't substantially given thought to those questions before that. What's your recollection of the previous times when you were on the Committee of how much engagement there was with hepatitis, particularly non-A, non-B?

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

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

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

A. Yes.

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

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

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

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

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

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

Then a little further on:

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

That's what Dr Hay's letter said.

A. Mm-hm.

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

We can see that:

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

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

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

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

Q. It also mirrored what Dr Lee had said?

A. Yes.

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

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

"Most authorities accept that, of those individuals who have been exposed to the hepatitis C virus, 50% will develop chronic liver disease and that approximately 20% of these patients will have cirrhosis of the liver. There is also now increasing evidence that hepatocellular carcinoma is a complication of chronic HCV liver disease."

So Professor Preston appears to be giving rather different statistics to Dr Hay in his letter, is that fair?

A. Um, slightly. I think -- and again, I'm not a hepatologist, but chronic liver disease was referenced in Dr Hay and Dr Lee's evidence. And I think the 20% -- the key figure there is the 20%, which I think accords with effectively what was then reported back as being the population which might have significant problems.

Q. Well, in Dr Hay's letter, he indicated that probably of the order of 80% to 85% will never suffer any problems from liver disease. That is quite a different statistic to 50% developing chronic liver disease, isn't it?

A. Probably. Again, I'm not an expert --

SIR BRIAN LANGSTAFF: Well, you don't have to be an expert, do you, to understand that 15% not having problems is rather different from 50%?

A. I think -- I think my interpretation or my understanding was that the chronic liver disease need not necessarily cause significant problems. And that

was what the other doctors were saying, I think -- I believe.

SIR BRIAN LANGSTAFF: I see.

MS FRASER BUTLIN: Was there any discussion at the meeting of the project team about the fact that you had Dr Hay saying one statistic and Professor Preston giving a rather gloomier statistic?

A. I don't recall.

Q. Was there any -- well, why did the project team decide to accept Dr Hay's view over Professor Preston's?

A. I don't recall specifically but I think it probably would have been because there was a feeling that that was the consensus. As I say, I don't think there was a feeling at the time that the differences were that significant. But I don't recall the meeting, you know, specifically.

Q. With different opinions from different clinicians, was there any discussion about the need to explain to members that the position was not clear-cut?

A. I don't recall. I think, you know, the situation did develop and, fairly soon after this, you know, we started doing much more activities and -- as understanding developed. But I don't recall the discussions taking place at that meeting other than what is minuted.

Q. With the benefit of hindsight, in relation to that early period, that initial period, do you consider that the risks of hepatitis C were downplayed in the information that was provided to the Society by some clinicians?

A. I think that's probably the case, and I think it's notable that whilst the group was formally stood down, within a few months, from the beginning of the following year, it was resurrected again because I think more information was coming forward and it was developed. But I think you're right. I think that the tendency was for clinicians -- and again, speaking purely personally, as somebody who would be talking to my clinician, the general sense was: look, this is not something particularly for you to worry about.

Q. And do you think that because you'd had those discussions with your own clinician, that might have influenced how you read the information from Professor Preston or Dr Hay and which you gave greater credence to?

A. That's possible, but I wouldn't have been alone. Again, you know, we were all -- well, some of us were patients, so, again, we would have had those conversations. You know, that's always possible.

Q. You said a moment ago that the team was resurrected

and I want to go to that now.

Could we turn to HSOC0017237, please, Soumik. These are minutes of a meeting of the Policy Committee on 15 April 1992, and I want to go on to internal page 4, please. Thank you.

And at the bottom of the page we can see the heading "Hepatitis", and we can see that:

"Mr Cowe said that in 1991 a Project Team had looked at hepatitis, reported its findings and been discharged, but since then concern had been voiced that the matter was not as cut and dried as had been thought. A statement of the Society's policy on hepatitis had appeared in *Update* April 1992, and a fact sheet was in the pipeline."

Can you help us just in relation to how this understanding had come about? How was the concern raised?

A. I'm afraid I don't recall.

Q. If we then read on it says that:

"Mr Barker said that he thought the Society should adopt a stronger, more active position as various developments weretaking place, such as the development and availability of Interferon."

What was meant by him in relation to taking a "stronger, more active position"?

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

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

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

Q. Soumik, could we --

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

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

A. Yes.

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

Soumik it's HSOC0003289.

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

"It was agreed ..."

I think it should say:

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

Then secondly, under "Possible future activities":

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

Then finally, towards the end of the page:

"The meeting then went on to discuss recommendations for a Hepatitis Awareness Campaign for [People With Haemophilia]. After discussion a format was agreed whereby a series of meetings could be held at seven venues throughout the UK where medical and legal aspects of hepatitis would be presented ..."

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

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

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

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

A. Okay, okay:

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

Was that whatactually took place or do you think that --

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

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

A. No, no, no.

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

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

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

A. Mm.

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

A. That was, as I said earlier, it was really to be able to give a slightly different -- the nature of the relationship between many patients and their doctor was a very long-term one and sometimes a very close one. And we felt that it would be -- people might be able to ask more difficult questions of a doctor who they weren't seeing on a regular basis, and things like that, but we felt that it might just facilitate a much more freedom of discussion in the Q&A which individuals might have.

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

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

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

A. I have no recollection of that discussion.

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

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

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

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

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

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

Do you recall what those concerns were?

A. No.

Q. Under f), we see:

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

And:

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

We then have views expressed.

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

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

Why was that your view at the time?

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

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

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

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

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

"... expressed concern regarding the dissatisfaction of the Manor House Group, if the Society was not seen to be doing something. In response to this David Evans stressed that the Society was clearly attempting to provide more information and promote better treatment for its members."

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

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

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

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

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

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

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

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

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

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

A. No.

Q. -- proportion of people?

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

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

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

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

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

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

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

A. Mm-hm.

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

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

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

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

A. Yes.

Q. -- we can see that:

"An informal meeting (ST and GB) ..."

So yourself and Mr Barker?

A. Mm-hm.

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

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

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

Q. Tactically, in hindsight, would this have reduced your firepower, your strength -- position of strength with the Department of Health?

A. No, I don't think it would, because, you know, we -- effectively we changed our mind fairly quickly thereafter, when we started seeking financial support for people. So I don't think it made any difference, particularly. But I would like to remember -- I wish I could remember quite why we said that.

Q. And indeed, if we go back to the beginning of this document, to the January '95 notes of the campaign group, in the middle of the page we've got a heading "Clarification Of What The Society Wants", and we can see --

A. Ah, right, there we are.

Q. -- that in January '95:

"Financial help to individuals is one of 4 objectives ..."

A. Yes.

Q. And (b) and (c) then deal with seeking:

"More equitable treatment between HCV infected and HIV infected."

And then:

"Modification of [the] Macfarlane Trust deeds ..."

Having told the Department of Health in December

in an informal meeting, and indeed, as you say, in the press release, that you were not seeking compensation, at what stage did you then go back to them and say, "We are seeking financial help"?

A. This is the same document, isn't it? It's just an earlier part of it. I just want to have the timeline right in my mind.

Q. Of course.

A. I would imagine that we -- sorry, I've got to be more specific.

I do not recall directly. However, I think that the line of thinking was probably similar to which -- that which had been through the HIV campaign, which was that if we started talking about compensation, they would parrot back the same statement that they had said about HIV, which is, "Well, sue us, then. Go to the courts."

So I'm thinking that, in all probability, we were seeking, as I say, a similar approach to that which we'd taken with HIV, which was to seek financial support, which might have allowed the Government, how shall we put it, a way out, as it were, rather than backing them into the litigation corner, if that makes sense.

Q. So that was January 1995.

A. But, as I say, I don't recall specifically, but that's my belief in the kind of thinking which probably would have been taking place.

Q. They were the meetings from January 1995, and we know that the campaign was officially launched on 14 March 1995.

A. Mm-hm.

Q. Then you served on the Executive Committee until 1996 --

A. Correct.

Q. -- before stepping down in 1998?

A. Correct.

Q. During that period, from March 1995 until you stepped down in 1996, how successful would you say the campaign was over that time?

A. In terms of outcomes, it was not very successful. I don't recall. In terms of what I might call inputs, ie, the effort put into it, I think it was quite considerable, you know, but the letters to MPs, you know, the representations to Government, use of the media and things like that, you know, I think we made a considerable effort during the course of the campaign, you know, in that period.

But I don't recall specifically that -- I think the one thing it might have done, if I recollect, is

that we might have got agreement on funding for interferon. I believe that we got that, yes. So in March 1996 we got the Government achieved -- agreed that they would provide funding for interferon treatment for indicated people with haemophilia and hepatitis C.

Q. The campaign continued even while you were not on the Executive Committee --

A. Mm.

Q. -- and you returned in 1998.

A. Correct.

Q. I want to move on to September 2000.

A. Right.

Q. By then, there were ongoing questions about whether the Society should be continuing with the hepatitis C campaign.

Soumik, please can we have HSOC0000365. I'm afraid I think I've given you the wrong reference. Just a moment, Soumik. I hadn't -- it is that reference. HSOC0000365, but it's the second page of the document, please.

We have here a lengthy letter that you wrote to Chris Hodgson in September 2000, and you're placing on record, you say, four points. The first, under number 1:

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

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

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

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

And the review which took place in the end of

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

Q. September 2000.

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

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

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

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

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

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

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

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

A. Yes.

Q. -- that informed your --

A. Yes.

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

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

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

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

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

A. **(Witness nodded)**

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

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

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

'... to ensure that the Society operates within the guidelines ... the trustees would first need to explore the possible success and viability of the campaign (both from a financial and legal point of view). It will also be necessary for the Society to obtain medical evidence to support the campaign, and this, together with any legal or other evidence, must be presented objectively and responsibly'."

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

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

Then at the bottom of the page:

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

Is that your recollection of what took place?

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

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

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

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

A. Mm.

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

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

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

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

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

Q. Then at the bottom of the page we can see that:

"Following further discussion it was proposed by [you, and then seconded] that:

"'The campaign objectives are exclusively:

"'a public inquiry into blood borne infections

"'a hardship fund which would be a fixed total sum for the benefit of individuals affected by HCV on a case by case basis on evidence of hardship [and]

"'recombinant for all'."

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

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

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

A. Yes.

Q. -- broadly --

A. Yes.

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

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

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

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

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

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

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

A. Mm-hm.

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

Could we have a look at HSOC0029476_076.

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

"Ken Milne reported that meetings would be held with representatives of the various pharmaceutical companies over the coming months."

And, a little further on, that he would be joined by you at those meetings.

Did you in fact attend any of those sorts of meetings?

A. No. With one exception: I do recall going to BPL to see their plant at Elstree in order to see the GMP, the good manufacturing processes, which was the main objective of the exercise. So it was a way of trying to reassure us about the safety of the production process of blood products. But in fact, I didn't -- I was still in full-time employment at that point, and so my availability and time to go to external meetings during working hours was limited.

Q. But others did go to those sorts of meetings, it seems.

A. Um --

Q. Is that your recollection?

A. It's possible. Ken was a scientist by background and I think he would have taken the lead on many of those meetings, but I don't recall who else might have gone.

Q. When there'd been a meeting or a visit with a pharmaceutical company or with BPL, was that information then conveyed to the Executive Committee?

Were they told about what was talked about?

A. Um, yes. Probably fairly informally. These were not sort of very formal meetings, they'd be more sort of 'get to know' meetings, this is what we're doing. It would have been reported back probably through the Blood Products Committee. But I don't recall specifically.

Q. Similarly, when you went to visit BPL, I think in 1994, the minutes suggest, did you convey that information back to other members of the Committee?

A. I may have done but, again, it wouldn't have been a -- it would be more of, you know, "I went to BPL, you know, I couldn't see any mice running around the laboratories". It was a pretty informal kind of process, as it were.

Q. In relation to both your visit to BPL and the other visits to pharmaceutical companies, did you and the Committee consider that these organisations might have had a vested interest in showing you that their products were safe? Was there any sense of whether they had an interest in showing you particular things?

A. Well, they certainly had a -- I would hope to think that they had an interest in showing everybody that their products were safe. And given the record, particularly, of the commercial pharmaceutical

companies, I think it was appropriate and necessary that we should occasionally seek opportunities to interrogate them on their processes. Given the history, as it were.

Q. And when you've come to speak about funding from pharmaceutical companies, pharmaceutical companies providing funding for things with the Society, you've said in your statement that your view was one of wary cynicism.

A. Yes.

Q. What do you mean by that?

A. We were very clear that, you know, we were very small charity, with very limited resources. And we were aware, with the commercial companies, that they had -- were, we believed, complicit, as it were, along with the failure of Government policy, in having infected us all with HIV or hepatitis C. And consequently, you know, we didn't trust them. But we were reasonably happy to take a bit of cash off them, you know, to support our activities in dealing with a situation which they had, in part, caused.

Q. Given that the Society was small and, as you say, did accept the funding from the pharmaceutical companies, in the minutes it seems that the funding was for specific activities.

A. Yes.

Q. For publications or seminars.

A. Yes, yes.

Q. Without that funding, would those activities have taken place?

A. It's impossible to say, as to what decision we might have made otherwise. Generally, we would have tried to carry on with those activities. They would be deemed to be priority activities, and we would have tried to carry on doing them. And it was only after we had identified the particular activities that we would go and see if we could get sponsorship.

But it's impossible to say what decisions we would have made with resources and priorities, you know, in that hypothetical situation.

Q. How did the Society, the Executive Committee or Board of Trustees, address that tension between wanting the money, so that the activities could take place, but what you've described as the cynicism in relation to the pharmaceutical companies?

A. I think it was pretty straightforward. The -- I'll be blunt, you know, we would try and screw them for as much as we possibly could.

Q. Was the tension discussed? Was it a matter that was spoken of in the Committee, that they weren't to be trusted but we'll have their money, thank you very much?

A. I think it was a general consensus view and, you know -- I think it was a general consensus view. We might not have been quite as blunt as I've just put it.

(Pause)

MS FRASER BUTLIN: Sir, those are the questions I have for Mr Taylor. I obviously need to see if there are further questions to be asked from the recognised legal representatives. We're just ahead of lunchtime.

SIR BRIAN LANGSTAFF: Very well.

Well, we'll take a break now until five to two. And come back and see what further questions we may have. That gives you long enough, I think.

MS FRASER BUTLIN: It does. Thank you, sir.

SIR BRIAN LANGSTAFF: Very well. Five to two, Mr Taylor.

(12.49 pm)

(Luncheon adjournment)

(1.55 pm)

(Proceedings delayed)

(2.10 pm)

MS FRASER BUTLIN: Mr Taylor, I have a series of questions from the recognised legal representatives so they cover several of the themes, so they may feel a little

bit scattergun.

First of all, when you first arrived at the Society in 1985, what established relationships did the Society have with non-haemophilia clinicians? For example, hepatologists or virologists?

A. Probably very few, I think is my recollection because, up until that time, it hadn't really been an issue, as it were, but I don't recall that there were, particularly at that point, strong relationships. As the HIV -- the impact of the HIV epidemic became more apparent, then they did have -- they did develop relationships. So for example, I recall, I think it was either in 1985 or 1986 at the annual general meeting, the Society invited Dr Richard Tedder, who was the leading epidemiologist in HIV, to come and give a talk. So they did develop as things progressed.

Q. With the benefit of hindsight, could an independent medical view, from non-haemophilia clinicians, should it have been sought sooner?

A. Possibly with hindsight, but again, you know, it's always easy to look at things in hindsight.

Q. In relation to the Medical Advisory Panel, were you aware, or was the Committee aware, that several of the members of the MAP were instructed by the defendant as

expert witnesses in the HIV litigation?

A. I was not aware of that, and I can't -- I don't know whether the rest of the Committee were aware of that.

Q. So you don't recall any discussion about any possible conflict of interest in that regard?

A. No, no.

Q. In relation to the decision to openly say to Government that there were poor prospects of success on a compensation -- on litigation in relation to HIV, who made that tactical decision to say that?

A. I would think it was probably a consensus decision to make it clear to the Government that they were effectively, as I said, being disingenuous in proposing a path of action which was not going to succeed in providing help and support on an immediate basis to people who urgently needed help and support.

Q. When we were discussing the HIV litigation, we discussed whether the concerns about supply of concentrates influenced the Society's position on litigation. Could we look at HSOC0029476_061, please, and could we go to page 3.

At the top of the page, "Compensation claims", we see:

"[The World Federation of Haemophilia] had also circulated a paper advising against the pursuit of

compensation claims. This resolution had its base in the [US] where it was feared that actions brought against individual pharmaceutical companies could lead to a 'drying up' of the concentrate supply. Since it was felt that action against companies in the UK was only one option -- and perhaps the least likely to succeed -- it was suggested that we should reserve our position by voting against the resolution. This was proposed by Mr Taylor, seconded by Mr Knight and agreed unanimously."

Do you recall this meeting and this resolution?

A. Not specifically, but I think it goes to show that we didn't allow the possibility of said drying up or litigation against companies. We kept that option open, and we voted against this resolution, in order to keep that option open. And I don't recall that the "drying up" of supply was a contributory factor in our decision making.

Q. This morning we discussed two letters from Dr Hay and Professor Preston about hepatitis C.

A. Mm.

Q. If we could have HSOC -- sorry, I've got a different, just a different reference, give me one moment. HSOC0003297. Yes. Sorry.

And if we could turn to page 4 of the document, please. When we spoke about whether there was a difference between Dr Hay and Professor Preston, you said that your interpretation, your understanding was that the chronic liver disease need not necessarily cause problems and that there wasn't in fact a difference between the two letters. If you look at the first paragraph of this letter in the middle, it says:

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

Is that where your understanding came from?

A. Yes.

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

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

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

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

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

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

A. Mm-hm.

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

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

SIR BRIAN LANGSTAFF: Do you mean 1986?

A. No, 1996, for hepatitis.

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

A. Sorry. Definitely '96.

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

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

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

A. Yes.

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

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

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

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

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

A. Well, we still had ... we had -- during the 1980s, or from when I was involved, 1985 through to the early '90s in particular, you know, you had -- on the one hand you had hysterical media coverage about HIV, which seriously impacted virtually all of our members in some way or another. Because, as I think I've already mentioned, haemophilia became a marker for HIV. And so you had people -- as I said, children who were being discriminated against at school, people whose job prospects were being put under threat, their homes were vandalised, and so we were dealing, as a Society, with a flood of requests for help and support coming in. So we had that.

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

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

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

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

Sir, those are the questions.

Question from SIR BRIAN LANGSTAFF

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

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

advice says we're going to fail".

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

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

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

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

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

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

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

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

A. I've got a brief statement, if that's all right. I just wanted to say, first of all, how much I welcome this Inquiry, decades late, and too late for so many friends and colleagues. But I really very much welcome this Inquiry.

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

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

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

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

HIV and hepatitis C were new and emerging threats that were poorly understood for many years, particularly in the case of hepatitis C. As is frequently the case with emerging threats, the scientific and medical advice was frequently confusing, conflicting, incomplete and, with hindsight, some of it was incorrect.

But I'd like to believe that we always acted in the utmost good faith.

The Society and the great majority of our members did not believe that, for the most part, haemophilia clinicians were negligent. Time and time again, we were told that individuals did not want to take legal action against their doctors.

By and large haemophilia clinicians cared deeply about their patients and acted in good faith in their treatment. Accordingly, the focus for Society's campaigns was always to persuade Government to meet its moral responsibility for its negligent behaviour.

I, and the Society, have always been convinced that the root cause of the disaster, and in particular its scale, were the inherently unsafe practices and processes connected with paid blood and plasma collection in the US and elsewhere in the 1970s. It was a risk recognised by the UK Government, and by Dr David Owen as Health Minister when he made the commitment to UK self-sufficiency in 1975.

It was then the failure of successive UK Governments to implement this commitment that led to

the prolonged reliance on imported blood products, that in turn infected so many of us with HIV and hepatitis C.

Whilst much of a focus of the Inquiry to date has been on the actions of medical professionals, and now on the Society and other campaigners in due course, I believe that most of us whose lives were devastated will be focusing on the evidence from Government that is yet to come, as to why self-sufficiency was not introduced when it had been promised, and why they were content to place the safety of British lives in the hands of foreign companies who had a proven record of playing fast and loose with product safety.

Individuals on the Trustee Board itself were living under the personal pressures of living with haemophilia, HIV and hepatitis. No one could seriously suggest that the trustees were not taking the issue seriously when so many of our own members were infected and we were working alongside friends and colleagues who we watched become ill and die, knowing that this same fate awaited ourselves.

During my time on the Executive Committee, at least six of my trustee colleagues died from HIV. And personally, another six of my friends from school also

died.

I would contend that for such a small charity, whilst the outcomes of our campaigns remain unfulfilled to this day, what was achieved was truly remarkable and is a testament to the staff and volunteers involved, and my thanks goes to all those over the years who have kept this issue alive. Thank you.

SIR BRIAN LANGSTAFF: Thank you very much. You have filled in some of the gaps for us, that we had, in particular evidence covering the campaign which The Haemophilia Society ran successfully for getting some money, at any rate, out of the Government, the story of the birth of the campaign, in respect of hepatitis C, and generally you've illuminated other evidence we have already heard, but you've illuminated it further in respect of the Macfarlane Trust.

So I would just like to thank you for giving the clear evidence you have. Despite what you said at the start would be a gap in your memory in the 1990s, it doesn't seem to have affected you very much and I'm very pleased about that. So thank you.

A. Thank you.

SIR BRIAN LANGSTAFF: Tomorrow.

MS FRASER BUTLIN: Tomorrow the Inquiry will hear from Ms Karin Pappenheim. I think she will be remote.

SIR BRIAN LANGSTAFF: She will be remote. So tomorrow 10 o'clock, to be heard remotely, obviously screened here for those who are here.

(2.33 pm)

(Adjourned until 10.00 am the following day)

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