

Tuesday, 9 February 2021

(10.00 am)

SIR BRIAN LANGSTAFF: Ms Richards, can you hear me?

MS RICHARDS: I can, sir.

SIR BRIAN LANGSTAFF: Let me describe for those who are watching what the position is. Mr Watters, you're speaking from home, aren't you?

THE WITNESS: I am.

SIR BRIAN LANGSTAFF: Are you on your own there?

THE WITNESS: I'm accompanied by a dog who can sometimes be a little noisy and my partner. But they are in another part of the house.

SIR BRIAN LANGSTAFF: Right. Let's hope the dog manages to control himself.

I'm at home too, restricted in travelling by the weather in this part of the country. Ms Richards, can you describe for us what the position is like in Fleetbank House?

MS RICHARDS: Certainly, sir. I'm here with Ms Fraser Butlin. We have one member of the Inquiry solicitor team. We have our document display engineer and a couple of members of the Inquiry team to ensure the smooth running of the hearing, and we have Mary to swear Mr Watters.

SIR BRIAN LANGSTAFF: Mr Watters, you are speaking not

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A. Yes.

Q. Your job title for the first five years was co-ordinator and then in 1986 your job title changed to general secretary; was there any difference between those two roles?

A. Absolutely no difference whatsoever.

Q. You have told us in your statement that when you arrived you had little or no idea of what the job was going to entail and there was no desk or office for you; is that correct?

A. Absolutely correct. It was quite a surprise because I'd come through a very rigorous selection process and then I rang the door bell and was met by a blank-faced secretary who kind of said, "Yes, who are you?"

Q. Can you tell us at the time you joined The Haemophilia Society, leave aside for the moment Executive Committee members, trustees, because we will come on to that in a moment, in terms of other employees working in the office, how many were there?

A. There were two part-time secretaries who worked mornings only.

Q. Now, in terms of your role and responsibilities, can you give us a broad idea of what your job entailed when you took up the role in 1981?

A. It was very largely administrative. There was all

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just to me and to Ms Richards and to those who are in the hearing room but to what I expect to be around about 200 viewers, both on YouTube and on a direct feed, around the country. They will be at home, I imagine, in very much the same sort of position as you and I are. So bear in mind that when you're speaking, you're speaking to a much larger audience than you will see on the screen.

Without more ado, I am going to ask Mary to ask you to take the oath. Mary, would you do so please?

DAVID GEORGE WATTERS, sworn

Questions by MS RICHARDS

MS RICHARDS: Mr Watters, can you see and hear me okay?

A. I can, indeed.

Q. I'm going to start by asking you some general questions about your job and your responsibilities at The Haemophilia Society and about The Haemophilia Society's organisation and structure. Before you joined The Haemophilia Society you had undertaken various jobs, broadly speaking in the charitable sector; is that correct?

A. That's correct.

Q. Then you joined The Haemophilia Society in early 1981, I think we got documents that suggest your appointment was discussed and confirmed on 28 January 1981?

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kinds of administrative things that had slipped and needed close attention. I also, of course, had to learn more and more about haemophilia itself and try and build up a credible office that could do a credible job that was fit for purpose.

Q. You say in your statement you had to spend some time learning to know the ins and outs of haemophilia and you spent some time out in the field with Haemophilia Centre Directors. Before you started, did you have any knowledge of haemophilia?

A. I knew it was a bleeding disorder.

Q. But that was it?

A. That was it.

Q. Was there any kind of training programme organised for you by the Society itself when you arrived?

A. Well, part of that training programme was going out into the field and meeting people. Of course, I learnt a lot from Executive Committee members who either had haemophilia or were partners of, parents of people with haemophilia as well.

Q. In terms of the time you spent with Haemophilia Centre Directors when you started, in order to learn the ropes, do you have a recollection of which centres you went to and what the process entailed?

A. I was quite sure that I went to St Thomas', the

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1 Royal Free and Newcastle and, if patients allowed,
 2 I sat in on the consultations but only with their
 3 consent.
 4 **Q.** Roughly how long would the time you spent at
 5 a haemophilia centre be, as part of this training
 6 exercise; a day?
 7 **A.** Possibly two to three hours in an afternoon possibly,
 8 yes.
 9 **Q.** You said there was a whole process of tax reclaims you
 10 had to sort out and other organisations you had to
 11 liaise with. What did that entail?
 12 **A.** Well, the tax claims hadn't been made for seven years.
 13 In fact, they went back so far that the Inland Revenue
 14 had to pay interest on the payments, but there were
 15 all sorts of organisations like The British
 16 Association of Social Workers and their special
 17 interests group and The Nurse's Association and
 18 related bodies and latterly, of course, liaising
 19 closely with HIV and AIDS organisations as well.
 20 **Q.** One of the issues you flagged up in your witness
 21 statement that you had to deal with from a relatively
 22 early stage was providing assistance for people with
 23 haemophilia in terms of accessing welfare benefits.
 24 What did that entail? What was the problem there?
 25 **A.** Well, the claiming process isn't exactly simple or

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1 **A.** Oh absolutely, absolutely.
 2 **Q.** If we look at one document where there's a brief
 3 description of some parts of your roles and
 4 responsibilities, Soumik, it's HCDO0000276_033,
 5 please. If we go to what I hope is going to be
 6 page 12, Soumik -- at least it's got a page number 12
 7 in the bottom left-hand corner. That's it.
 8 So we can see there this is from the annual
 9 report of 1986. So this is the point in time at which
 10 your job title changed. It says:
 11 "The Co-ordinator experienced a re-incarnation
 12 and emerged as the General Secretary, a title which
 13 describes more accurately his present position in the
 14 Society and the functions he performs."
 15 Then the next sentence describes
 16 responsibilities:
 17 "He is responsible for the day-to-day
 18 administration of the Society's office and its staff,
 19 as well as for general communication with the
 20 Society's members by correspondence and telephone. In
 21 addition, he has special responsibilities in
 22 connection with Mobility and Attendance Allowances
 23 often supporting members personally when they attend
 24 Appeal Tribunals."
 25 That's a very general description but is it

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1 straightforward so people needed help framing their
 2 applications. Eventually, we produced a document to
 3 help them do that specifically for haemophilia but
 4 claims hadn't been encouraged and so we had to go
 5 about an encouragement process. Very few claims
 6 succeeded first time round because this was a kind of
 7 new area for the benefit system to cope with. But --
 8 and so I frequently had to go to appeal tribunals and
 9 assist appeal tribunals. But we ended up winning
 10 cases hand over fist and got a particularly helpful
 11 decision by Social Security Commissioners which helped
 12 cases.

But, of course, this applied to people who had
 not benefited earlier in their lives from home therapy
 and all the benefits that followed from that and the
 younger generation, of course, having had the benefits
 of home therapy since birth almost, they had none of
 the damaged joints and risks that the older guys
 faced.

So that process kind of came to an end.

Q. Was it your impression in those early years of
 assisting people with their welfare benefit claims
 that the welfare benefit system had a poor
 understanding of the problems faced by people with
 bleeding disorders?

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1 a reasonably accurate one?
 2 **A.** That is a fairly accurate description, yes.
 3 **Q.** You said in your statement that you would report to
 4 the chair and to the board, and I'll come onto the
 5 Society's structure in a moment, but to what extent
 6 did you have autonomy in terms of the decisions you
 7 took? Your statement suggests that you worked very
 8 much under the direction of the chair and board; is
 9 that correct?
 10 **A.** That's correct. I mean, of course, there were on the
 11 hoof situations where you had to take action
 12 immediately, like you couldn't go and consult the
 13 Chairman while you had somebody holding on the line
 14 for advice to give them, and things like that, yes.
 15 **Q.** I'm going to then ask you a little about the Society
 16 itself, first of all, its aim and objectives.
 17 Soumik, could we have PRSE0003316, please.
 18 We can see this is a publication called Group
 19 Seminar Proceedings from December 1981. Just so that
 20 we understand what this is, there was a group seminar
 21 held at this time on an annual basis, roughly, was
 22 there?
 23 **A.** Roughly, roughly, yes.
 24 **Q.** This is the subsequent publication of what took place
 25 at the seminar?

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1 A. Correct.

2 Q. If we could go to page 12, please, Soumik, we can see

3 there's an article entitled "The Aims and Objects of

4 The Haemophilia Society (Based on a talk by Ken Milne

5 at the Society's Seminar held on 15th March 1981), and

6 then we can see if we go a little further down the

7 page it says:

8 "The aims and [objectives] of the Society are

9 set out in the Society's constitution. They are:-

10 "(a) To provide a fellowship for sufferers from

11 Haemophilia and allied conditions, their families and

12 those concerned with their health and welfare."

13 Mr Milne's observation is that that's given as

14 the Society's first aim. (b) then is:

15 "To safeguard social and economic interests of

16 such sufferers."

17 (c) is:

18 "To promote the study of the cause and

19 treatment of haemophilia and allied conditions."

20 If we go up to the top part of the page again,

21 please, Soumik:

22 "(d) To gather and publish information useful

23 to sufferers and the general public."

24 I'm just going to read what Mr Milne says

25 there, Mr Watters:

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1 recognised by most professionals in the field of

2 haemophilia care. The Society has been in the setting

3 up of the Haemophilia Nurses' Association and the

4 Haemophilia Special Interest Group of the British

5 Association of Social Workers. Moreover, the Society

6 is invited to send observers to the annual meeting of

7 the Haemophilia Centre Directors."

8 We'll come back to that, Mr Watters.

9 (f) then is:

10 "To co-operate with any the other Societies or

11 bodies having similar aims."

12 And Mr Milne identifies notable among other

13 bodies the World Federation of Hemophilia.

14 (g) is:

15 "To provide financial help where necessary and

16 practicable.

17 "(h) To do all other things which may legally

18 be done in the furtherance of the Society's objects."

19 Does that reflect your understanding of the

20 aims and objectives of The Haemophilia Society during

21 the time that you worked there?

22 A. Absolutely, absolutely.

23 Q. If we go to another document on the question of the

24 Society's aims.

25 HCDO0000276_033, please, Soumik. It's the

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1 "This is an aspect of the Society's work on

2 which we place great emphasis. We regard our

3 publications as of great importance, particularly

4 The Bulletin, but also the pamphlets we produce, such

5 as 'Notes for Teachers'. These are all distributed

6 throughout the world, as many other Haemophilia

7 Societies find them useful."

8 Just pausing on that aim, Mr Watters, was the

9 publication of documents such as The Bulletin, and

10 we'll look at ones like Haemofact later, but was this

11 the main means by which the Society communicated

12 information to its members?

13 A. Yes, it was, yes.

14 Q. Then we have -- sorry, carry on?

15 A. I was going to say that The Bulletin was the main

16 method but the local groups were another method, which

17 was a more local information source, but they would

18 glean most of their information from The Bulletin.

19 Q. I'll come on to ask you about the local groups in a

20 moment. Then we see (e):

21 "To co-operate with the medical and allied

22 professions for the furtherance of the objects of the

23 Society."

24 And it said:

25 "The value of the Society's co-operation is

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1 document we had earlier this morning.

2 This is, again, the 1986 annual report. If we

3 go to page 5, please, under the heading

4 "Introduction", this document describes the aims of

5 the Society in perhaps a shorter and more concise and

6 focused way. It says this:

7 "The aims of the Society are:

8 "(a) To promote research into and the study of

9 the causes, diagnosis and treatment of haemophilia and

10 all related blood disorders, including ... research

11 into and the development of processes, techniques and

12 drugs for the cure, prevention and/or control of all

13 such disorders, and to publish the useful results of

14 such research, and

15 "(b) To provide or assist in the provision of

16 the medical, surgical and pharmaceutical care and

17 treatment together with advice and aid (both financial

18 and in kind) for sufferers from haemophilia and all

19 related disorders who are in need."

20 Now, the focus there, Mr Watters, in part is on

21 treatment for haemophilia and bleeding disorders,

22 understanding treatments, providing information about

23 treatments. Did you understand that to be part of the

24 Society's remit as well?

25 A. Yes. Could I just point out that those aims are the

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1 aims contained in the documents relating to
2 incorporation rather than those pertaining to charity
3 law, and so they are slightly different, and more
4 broad brush, if you like. But yes is the answer to
5 your question.
6 Q. Thank you.
7 Now, in terms of the structure of the Society
8 in 1981, when you arrived -- we can take the document
9 down thank you, Soumik -- there was, as I understand
10 it, a board of trustees which was also known as the
11 Executive Committee?
12 A. Correct.
13 Q. So when we see Executive Committee meetings which took
14 place on approximately a monthly basis, those are the
15 same as the meetings of the Board of Trustees?
16 A. Correct.
17 Q. You've told us, broadly speaking, the members of the
18 trustees or the Executive Committee were people who
19 had some form of personal association with
20 haemophilia. Do you know anything about the process
21 for selecting the board members?
22 A. Selection was by nomination. There was no hidden
23 criteria or anything like that. One thing I would say
24 was that the term of office was entirely open and
25 there was no fixed period of service.

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1 Blood Products Committee:
2 "The purpose of this committee was to keep
3 under review and, in particular, to be constantly on
4 the back of the Department of Health about the
5 achievement of self-sufficiency in the
6 United Kingdom."
7 So your understanding was that that was one of
8 their main roles?
9 A. Correct.
10 Q. When you arrived in 1981, was it Mr Milne who
11 effectively led the Blood Products Committee?
12 A. Indeed.
13 Q. You've said, in terms of membership of that committee,
14 that you or your role -- that you probably had a part
15 to play in it but you don't recall the details of it.
16 Is this right: you weren't a member of the
17 committee but you would assist the committee, is how
18 I read your statement?
19 A. I would service the committee --
20 Q. What does that mean?
21 A. -- and if they wanted things found out, I would find
22 it out. If there were minutes to be taken, I would
23 take the minutes.
24 Q. You've also said in your statement that one of your
25 roles was to seek clarity and give others the

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1 Q. Is this right, that in terms of the board, the
2 Executive Committee, there were none on it who sat
3 there by virtue of a medical qualification?
4 A. No, no, no.
5 Q. Then below in the hierarchy, below the Executive
6 Committee, was the Council, which had two
7 representatives from each local group; is that right?
8 A. That's correct.
9 Q. The council, with the local group representation,
10 would meet with the Executive Committee I think two or
11 three times a year; is that correct?
12 A. Correct.
13 Q. Now there were a number of other committees. There's
14 the Medical Advisory Panel, which we'll come on to.
15 There was the Case Committee, whose role, as
16 I understand your statement, was to consider the
17 giving of financial grants to families in need; is
18 that right?
19 A. Correct.
20 Q. There was the Blood Products Committee. It's
21 sometimes described as the Blood Products
22 Subcommittee. Were there two committees or is that
23 one and the same thing?
24 A. It's one and the same, yes.
25 Q. Then in your witness statement you say this about the

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1 opportunity to respond. Could you elaborate upon that
2 a little?
3 A. I think that anybody who services a committee will
4 know that sometimes a committee can wander off the
5 point and my role at times like that would be to be
6 a good shepherd and bring the sheep back into the fold
7 onto the straight line again.
8 Q. Now, it's clear from some of the documents that we'll
9 look at, and some that we won't look at but which
10 I know have been sent to you for you to consider, that
11 the Blood Products Committee from time to time visited
12 BPL, it liaised with pharmaceutical companies, had
13 meetings with pharmaceutical companies, it met, from
14 time to time, with the Department of Health and we'll
15 look at a couple of those meetings.
16 Was that kind of work undertaken at the
17 direction of the Executive Committee or was the Blood
18 Products Committee very much its own master of what it
19 would do?
20 A. I would say partly both because the executive
21 committee charged the Blood Products Committee,
22 subcommittee, with a main role being the supply of
23 concentrates in the United Kingdom, whether they came
24 from BPL or from pharmaceutical companies who bridged
25 the gap, as it were, between what we produced at home

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1 and what was needed in order to meet the demand. It's
2 a complex situation because human plasma is the
3 derivative. It's not a chemical that you can create
4 and so it was very limited and the supply was fragile
5 on account of that.

6 **Q.** So supply was a key issue for the Blood Products
7 Committee. Was also safety and efficacy of products
8 a key issue for the Blood Products Committee?

9 **A.** Indeed, indeed. A very big problem was supply.

10 **Q.** Again, we'll look at that in a little more detail in
11 due course. Then there was the Research Grants
12 Committee. I just want to ask you a little about
13 that. So if we go, Soumik, please, to
14 HSOC0029476_033, please.

15 So these are really, by way of example, the
16 minutes of meeting of the executive committee on
17 9 February 1984. If we go, please, to page 3, Soumik,
18 and if we look at the top half of the page we've got
19 the heading there "Research Grants Committee", and
20 then we see it says:

21 "The Co-ordinator [that's you] reported that
22 the Committee had met earlier in the evening and
23 wished to make the following recommendations to the
24 executive committee ..."

25 Then there's a recommendation in relation to

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1 yes.

2 **Q.** So it's a subcommittee, as it were, of the Executive
3 Committee?

4 **A.** Yes. Occasionally if there was that, an application
5 may be discussed with the Medical Advisory Panel if it
6 was something that exceeded the knowledge of the
7 members of the Research Grants Subcommittee.

8 **Q.** Then we see this reference to the possibility of
9 restructuring the Grants Committee. I'm not going to
10 ask you to try and recall the details of that but
11 there's a suggestion here that the chair had written
12 to Professor Bloom to obtain his written views. Do
13 you know why Professor Bloom's views were being sought
14 on the restructuring of the Research Grants Committee?

15 **A.** I suspect, at that time, Professor Bloom was chair of
16 the Haemophilia Centre Directors Organisation.

17 **Q.** So you think he was being written to in that capacity?

18 **A.** In that capacity, yes.

19 **Q.** We can take that down, thank you, Soumik. Then the
20 next structural issue I wanted you to assist us with
21 is in relation to the role of the local groups. How
22 did the local groups operate and what was their
23 purpose and function, as far as you understood it to
24 be?

25 **A.** Could I just say something relating to research grants

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1 providing some funding to the Royal Liverpool
2 Infirmary, to the Lewisham Hospital and to the London
3 Hospital, and then if we look at the last bit of that
4 section, it says:

5 "Proposed restructuring of the Grants

6 Committee: The Co-ordinator had not been able to draw
7 up a paper to be tabled for this meeting and the
8 Chairman had written to Professor Blook to obtain his
9 written views. The matter would appear on a future
10 agenda."

11 Is this correct, in the Research Grant

12 Committee's remit, as the name would suggest, was to
13 consider applications made by clinicians and hospitals
14 for grants to undertake research?

15 **A.** That's correct.

16 **Q.** It would meet and form views on the applications and
17 then it would make recommendations, which would then
18 be approved or not approved by the Executive
19 Committee?

20 **A.** That's correct.

21 **Q.** Can you recall who sat on the Research Grants
22 Committee. I'm not looking for names but was it
23 members of the Executive Committee or was it
24 commissioned --

25 **A.** Oh, yes it would be members of the Executive Committee

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1 before we get there, which involves local groups and
2 council. If the Executive Committee approved a grant
3 that had to be referred to council at the next
4 meeting, for their endorsement before any payment was
5 made, and you will see reference to that in minutes of
6 council meetings.

7 **Q.** So the process was the Research Grants Committee would
8 consider an application or request. Its
9 recommendation would go to the Executive Committee and
10 if the Executive Committee was recommending that the
11 grant should be made that would be approved by the
12 council, which included representatives of local
13 groups?

14 **A.** Correct, yes.

15 **Q.** Thank you. So, yes, then the local groups, what was
16 their role and remit?

17 **A.** Their local group was to be the local presence of The
18 Haemophilia Society and, quite often, local problems
19 would emerge through the local group and be reported
20 to me and, after internal discussions, we would decide
21 whether to take any action on that. You know, it may
22 be something like some part of the country suddenly
23 found their Factor VIII supply was being changed
24 regularly or that there was a shortage of supply and
25 people weren't getting the treatments they needed.

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1 Q. If we look at PRSE0003316 please, Soumik. Again, this
 2 is the 1981 Group Seminar Proceedings publication.
 3 There's a detailed article on the role of local
 4 groups, I think -- I won't go to it but if anyone is
 5 interested from the perspective of the Northern
 6 Ireland group. If we just go to the last page of
 7 this, just to get a sense of the geographical remit of
 8 the groups -- so the last page. It should be two
 9 pages further on. That's it. Top half of the page,
 10 we see there that there are 28 local groups there
 11 identified and the map gives us an idea of geography.
 12 So we can see the rough spread there of the groups.
 13 Was it part of the remit of the local group to
 14 establish a relationship with the Haemophilia Centre
 15 Director for their local haemophilia centres?
 16 A. They would almost certainly have that already, because
 17 of the local groups consisted of people with
 18 haemophilia, and so they would have a link and that
 19 link, on the whole -- not always but on the whole --
 20 would be welcomed by Haemophilia Centre Directors.
 21 Q. We've seen some examples of newsletters produced by
 22 some local groups for their members. As far as you
 23 can recall, was that something that was done by all
 24 local groups or did it very much depend upon the
 25 individual local group?

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1 A. Well, most of the Executive Committee members had
 2 their own employments to attend to and so they were
 3 not as free to do that during the week. But they
 4 would attend seminar proceedings, which were always at
 5 a weekend.
 6 Q. Now, throughout the time that you were employed by The
 7 Haemophilia Society up to 1994, was the chair
 8 Reverend Tanner?
 9 A. He was, yes.
 10 Q. Then do you recall whether the Society had access to
 11 and was able to consider medical journals in order to
 12 try and keep up-to-date with developments?
 13 A. We received some medical journals and they normally
 14 sat in two piles, the Lancet and the BMJ, but we very
 15 rarely had time to read them. If an article was drawn
 16 to our attention or if I happened to spot it, it would
 17 be photocopied and circulated in weekly mailings to
 18 the trustees.
 19 Q. I've seen a reference from a 1975 meeting -- it's
 20 before your time, so I won't put it up on the
 21 screen -- but to Mr Milne referring to reading medical
 22 journals and the reading the Lancet. Do you know the
 23 extent to which the Blood Products Committee
 24 considered medical journals?
 25 A. I wouldn't know from this distance but I know that

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1 A. It depended very much on the capability of the local
 2 group and the skills of their members.
 3 Q. We can take that down, thank you, Soumik.
 4 Other than through the local group structure
 5 and the role of local group members on council, how
 6 else did The Haemophilia Society attempt to ensure
 7 that the voices and interests of all its members in
 8 all parts of the country were heard?
 9 A. Well, we had a telephone line which operated five days
 10 a week and there was an answering service on that. We
 11 were kept busy with correspondence from individual
 12 members. I mean, it may not sound a lot but there
 13 were sometimes five or six letters a day but when
 14 you're a very small organisation dealing -- with small
 15 staff dealing with five or six letters a day, some of
 16 which could raise complex issues, that was quite
 17 a lot.
 18 Q. To what extent in the course of the 1980s,
 19 particularly the first half of the 1980s, were you
 20 able to travel to attend local group meetings across
 21 the country? Was that part of what you did?
 22 A. That was part of what I did, yes.
 23 Q. Did others involved in the Society, Executive
 24 Committee members, did they travel or attend local
 25 group meetings on a regular basis?

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1 a lot of the extra burden of work that was done by
 2 subcommittee members passed to the office on my
 3 appointment and, of course, it was very soon after my
 4 appointment that the HIV and AIDS tragedy descended on
 5 us.
 6 Q. Then, again -- before we move to consider issues such
 7 as HIV and AIDS -- funding of the Society: how was the
 8 Society funded during the years that you worked there,
 9 to the best of your knowledge?
 10 A. Well, we must have sent out about 600 appeal letters
 11 every year and that was quite difficult when you were
 12 dealing with a manual typewriter. Computerisation was
 13 a huge blessing to us in that work.
 14 In addition to that, the pharmaceutical
 15 companies supported our work.
 16 Q. I'm going to come back to the topic of pharmaceutical
 17 companies later in the week.
 18 Then, in terms of the membership of the
 19 Society --
 20 A. Oh, I should add that local groups did raise vast
 21 amounts of money, which came to the national
 22 organisation.
 23 Q. Was that through local fund-raising activities?
 24 A. Local fund-raising activities. People worked
 25 incredibly hard and I wouldn't want my evidence to

24

1 pass without acknowledging that.

2 Q. Now, in terms of the members of the Society, you've

3 observed in your statement that it was only a minority

4 of individuals in the UK who were living with

5 haemophilia who were members of the Society. Is that

6 correct?

7 A. It's always difficult to know because haemophilia is

8 a family affair and it was difficult to know how many

9 people were represented by a single membership

10 because, if it was Mum and Dad and there were three

11 boys with haemophilia, you were covering an awful lot

12 more than, you know, the membership statistic would

13 show. But not everybody chose to be a member of the

14 Society and we're not all clubbable people, really.

15 Q. You have recorded in your statement that it was

16 reported in Group Seminar Proceedings in

17 February 1983 -- I won't go to the document -- that

18 there were 5,000 individuals with haemophilia in the

19 UK and there were 1,500 members of the Society.

20 A. That is possibly correct. From this distance,

21 I couldn't say definitely.

22 Q. In terms of membership of the Society, is this right,

23 that to be a member of the Society you did not have to

24 be a person yourself suffering from a bleeding

25 disorder. You could be a family member, for example,

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1 A. The membership application form would ask what type of

2 haemophilia it was, A, B or C, and so on and so forth.

3 Q. Did the Society gather and hold information about the

4 treatments that individuals were receiving for their

5 haemophilia?

6 A. No. Well, not to the best of my recall I have to add,

7 yes.

8 Q. You've described at various points in your statement

9 your impression of the Society when you joined it.

10 You've described it as "some 30 years behind in so

11 many ways" and as a "very ancient automobile". Can

12 you elaborate upon that? Can you help us understand

13 why and on what basis you say it was decades behind in

14 some respects?

15 A. Well, I'd been working in homelessness organisations

16 which had very slick management and function and

17 definition really, whereas The Haemophilia Society to

18 some extent had become -- there were a lot of people

19 who had been around for a very long time, put it that

20 way, and nothing much had changed. The offices were

21 a suite of four rooms, most of which were filled with

22 clutter that served no useful purpose at all, and

23 I remember there was great resistance to moving

24 anything, and I remember the first Easter that I was

25 there, I had the most massive clear-out, and a skip

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1 of someone suffering with a bleeding disorder?

2 A. Indeed, or someone interested, like a nurse or social

3 worker or -- yes. It was a sure way of getting all

4 the communications.

5 Q. Did you have any sense, from your dealings with

6 members or from your visits to local groups, whether

7 those with bleeding disorders who were members of the

8 Society, whether they were predominantly those

9 suffering from severe haemophilia rather than those

10 who had a milder form?

11 A. There was a spread but it would tend towards those

12 with the more severe disorders, yes.

13 Q. In the 1980s, can you recall what information the

14 Society held about its members? It would obviously

15 have a name and address but did it have information

16 about their condition or their treatment or their

17 haemophilia centre, or anything of that kind?

18 A. Well, pre-computerisation all that would be held on

19 paper, of course, and it was only with the advent of

20 computers that it was possible to record and form

21 basic statistics based on people's haemophilia status

22 and things like that.

23 Q. But prior to computerisation were there paper records

24 which held details about individuals, other than name,

25 address and membership number?

26

1 arrived on Friday and departed before we got back to

2 work on the Tuesday with what was just rubbish, you

3 know.

4 Q. Your statement suggests that there was a lack of

5 outreach and a lack of grasp of big issues.

6 A. It was very much based on the issues experienced by

7 the trustees themselves, who were attending the bigger

8 centres in London and not realising the predicament

9 that people were in attending our local hospital

10 out-patients department, where there was really no

11 informed knowledge of haemophilia by the medics who

12 were looking after patients and things. That was why

13 it was so important that the reorganisation and

14 classification of haemophilia centres took place, so

15 that everybody knew the point of reference and the

16 chain of command, as it were.

17 Q. You've also referred in your statement to there having

18 been tension which inhibited "necessary growth and

19 development". What was the cause of the tension that

20 you recall?

21 A. Well, there was huge tension about my appointment in

22 the first place -- not me personally but the

23 establishment of my post -- because that was felt by

24 a few to affect their personal power and authority and

25 they really wanted to hang on to that, and they saw

28

1 taking in outside staff as quite an infringement upon
2 their power base.

3 Q. What were the areas that you identified, once you had
4 joined, where you thought there needed to be growth
5 and development?

6 A. Just in outreach generally and giving patients across
7 the country a better voice, both through local groups
8 and through individual contact that -- the message
9 I really wanted to get across was: the Society is here
10 to help you, we're not here to help ourselves. Yes.

11 Q. You I think also said in your statement that a large
12 part of your role was helping members to trust the
13 organisation and see that the organisation had
14 a function and a purpose.

15 Had there been or was it your impression that
16 there was a problem with trust from members'
17 perspective?

18 A. It was an impression I gained, yes.

19 Q. That was from what? Your visits to local groups and
20 the like?

21 A. Visits to local groups, communications with it from
22 individual members and so on and so forth.

23 Q. What kind of action did you take or attempt to take to
24 bring the Society up-to-date, to try to make it more
25 purposeful?

29

1 Q. Now, in terms of the Society's relationship with other
2 organisations, you've touched on that already. In
3 terms of international relations, what was the
4 Society's relationship with the World Federation of
5 Haemophilia?

6 A. It was close, it was close. Father Tanner played
7 a leading role on the Executive Committee of that
8 body. I mean, like The Haemophilia Society in the
9 United Kingdom, they were a very small fledgling
10 organisation that really operated off the corner of
11 Frank Schnabel's desk in Montreal, and he had one
12 part-time secretary, dear Sheila. But our
13 relationship was close and I visited their offices
14 more than once, just in order to keep good
15 communication and good relationships going.

16 Q. Did Society members usually attend the congress that
17 was held by the World Federation of Haemophilia?

18 A. They could be held anywhere in the world and they were
19 quite expensive, but we did offer sponsorships to
20 individuals to come along with Executive Committee
21 members.

22 Q. Then were there other international bodies or bodies
23 located in other countries that the Society had
24 a particularly close relationship with?

25 A. We had very close relationships with the Haemophilia

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1 A. Well, improving communication, modernising some of the
2 systems, although it was difficult to modernise
3 a manual typewriter, really. But I do think we
4 introduced electric typewriters -- with memory banks.
5 I remember now, electric typewriters with memory
6 banks, which were transformative as well, a precursor
7 of the computer era. And just generally being more
8 approachable and friendly in all the communication and
9 contact with members.

10 Q. Were there any initiatives that you wanted to
11 introduce where you met with resistance from the chair
12 or the Executive Committee?

13 A. Absolutely not, no.

14 Q. I think you've told us that you reported to the chair
15 directly and you'd have regular meetings with him.
16 Were they on a weekly basis?

17 A. Almost on a weekly basis, yes.

18 Q. How did those meetings fit into the structure of the
19 Society's decision-making? Were there decisions that
20 the chair could make on your recommendation that did
21 not need to go through the Executive Committee?

22 A. They would be fairly minor matters. And -- but on the
23 whole, it was to keep the Chairman informed so that as
24 issues arose he knew the background to them and what
25 was in the picture.

30

1 Societies in Holland, slightly less so in France but
2 very strong relationships with Canada, the USA and
3 Australia. In fact, the then heads of -- my
4 equivalents in Canada and Australia, we remain close
5 friends to this day. We shared much pain together,
6 I can tell you.

7 Q. In the pre-email era, pre-computer era, how were those
8 relationships maintained? Was it a question of visits
9 being made to other countries or meeting at the World
10 Federation of Haemophilia or telephone conversations,
11 correspondence --

12 A. It largely would be meetings at World Federation and
13 communication in writing or by telephone, which was of
14 course very expensive in those days.

15 Q. Then, in terms of UKHCDO, I think we know from
16 documents that The Haemophilia Society had been
17 invited to send representatives to annual UKHCDO
18 meetings from 1974. Is this right, that The
19 Haemophilia Society's attendance was generally at the
20 annual general meeting of all Haemophilia Centre
21 Directors not the smaller meetings held by Reference
22 Centre Directors?

23 A. That's correct.

24 Q. What was the purpose of The Haemophilia Society's
25 attendance at those meetings?

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1 A. I suppose it was just to build bridges between the
2 national patient organisations and those involved in
3 treatment and care.
4 Q. You've described the relationship in your statement
5 as, I think, respectful and co-operative. Do you
6 think that the Society or individual representatives
7 of the Society who attended those meetings were
8 generally deferential to the Haemophilia Centre
9 Directors Organisation?
10 A. Yes, yes. But at the same time, we now know with
11 hindsight and reading papers that we otherwise
12 wouldn't have had access to that they possibly were
13 not quite as worthy of that deference as they were.
14 Q. We will come back to that but by that I think you
15 mean -- and please correct me if I'm wrong -- that
16 there was information during the developing AIDS
17 crisis that you think wasn't shared fully with the
18 Society?
19 A. Correct.
20 Q. We'll explore that over the course of the week. You
21 do say in your statement this about Executive
22 Committee members attending UKHCDO meetings, that they
23 were interrogating the physicians about their role and
24 their decisions and their view of the future. What
25 did you mean by that, by "interrogating the

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1 the Department took place?
2 A. Ministers fairly infrequently. Civil servants
3 possibly once a month. Remember, Trinity Street was
4 just round the corner from Alexander Fleming House.
5 Q. So there was a fairly close and regular arrangement or
6 line of communication between Executive Committee
7 members and the DHSS?
8 A. Indeed, yes, yes.
9 Q. To what extent were you involved in those? If
10 meetings were taking place perhaps as often as once
11 a month did that usually involve you or was that
12 Executive Committee members only?
13 A. That would involve me.
14 Q. I think we've got some notes and minutes of meetings
15 with ministers which, as you have said, were less
16 frequent. Were the meetings that took place with
17 civil servants minuted?
18 A. No. They would have formed the basis of possibly
19 a verbal report. There was never anything of all that
20 great a consequence emerged from those meetings and,
21 in a sense, it was amusing to go along and see how
22 well they were defending their position on that
23 particular month.
24 Q. In the early years that you were there, 1981/1982,
25 what was the main topic that would be discussed at

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1 physicians?"
2 A. Yes, "interrogation" in light of what I was reading
3 last night in the documents you sent over yesterday is
4 a very strong word. I think they were possibly
5 massaging them about the treatment and things like
6 that.
7 Q. So asking questions but not necessarily challenging
8 clinicians?
9 A. Absolutely, yes, yes.
10 Q. You've also described in your witness statement
11 a concern you hold now, I think, that the UKHCDO may
12 have been very secretive. By that do you mean
13 information not being fully shared with the Society?
14 A. Correct, correct.
15 Q. As I say, we'll come back to that.
16 Then, in terms of, again, with relationships
17 with others, I just wanted to ask you a little in
18 general terms about the Society's relationship with
19 Government. First of all, was the relationship that
20 the Society had essentially with the Department of
21 Health, the DHSS, rather than any other department?
22 A. Yes, indeed.
23 Q. We'll look at a couple of specific meetings but do you
24 have a recollection of how often meetings between the
25 Society and either civil servants or ministers within

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1 those meetings with civil servants?
2 A. You mean before the advent of HIV and AIDS?
3 Q. Yes.
4 A. It would be supply --
5 Q. So the BPL --
6 A. -- and self-sufficiency, yes.
7 Q. Then once we had the advent of the AIDS, and obviously
8 we'll explore this in more detail but let's just say
9 from 1983 onwards, did meetings with the DHSS with
10 civil servants continue to take place on a fairly
11 regular basis?
12 A. Yes, yes.
13 Q. Did AIDS become the primary topic at that time?
14 A. Oh, yes, very much so and, indeed, the financial
15 plight it was introducing to people who couldn't work,
16 families whose father had died and they faced great
17 hardship and compensation certainly took over as
18 a mainstream subject. But no doubt we'll explore that
19 later in the week.
20 Q. We will.
21 Then if we look at one further document
22 HSOC0010385, please, Soumik. We can see this is
23 an Executive Committee meeting in November 1991. If
24 we go to page 4, please, top half of the page, under
25 the heading "Policy Committee", you will see there in

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the second paragraph, Mr Watters, a reference to a meeting with Mr Waldegrave Secretary of State for Health. I am not going to ask you the detail of what was discussed, at least not at this stage, but if we look towards the bottom of that paragraph, you say this or you are recorded as saying this:

"Mr Watters remarked that the Society had done well to see Mr Waldegrave; it was a privilege to see a Secretary of State, not just ministers, and the Committee expressed satisfaction and approval."

So the impression that gives is it was rare for your meetings to involve the Secretary of State himself or herself, it was usually with junior ministers?

A. Correct.

Q. We can take that down, thank you, Soumik. I wanted to ask you next about the Medical Advisory Panel. If we go, Soumik, to PRSE -- sorry, we'll try this, HSOC0022901. This is a Bulletin from 1982. If we go please to -- I think it's page 7, Soumik -- oh, sorry, previous page. That it, "The Functions of The Haemophilia Society". We'll just pick up if we go back towards the top of the page, please, we can see there, the second paragraph down refers to the Medical Advisory Panel. It says this:

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and not from 9 until 5, but that was never terribly popularly received, I have to say.

Q. Then it says that there were few formal meetings with them as a Panel but a fairly continual exchange of information and advice. We're obviously going to look at some individual examples of correspondence by letter between you or the Chair with members of the Panel, but what do you recall from again the first half of the 1980s when you arrived? How did you interact with the Panel and its members?

A. I've really got no recollection of that at all. But I think that the relationship between the Society and the Haemophilia Centre Directors Organisation as a whole became more formalised as the years passed.

Q. Would you agree with the characterisation here of there being a fairly continual exchange of information and advice?

A. I think that's very generous view, given what we know now.

Q. Then it says in the last sentence:

"Their support has enabled us to open many doors that would otherwise have been closed to us."

Do you understand what that's referring to?

A. I can think of no such doors that were opened at all.

SIR BRIAN LANGSTAFF: May I just ask a question here.

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"The Medical Advisory Panel has no executive role in the Society, but we would ignore their advice at our peril! There is a fairly continual exchange of information and advice between the Officers and the Panel, although the formal meetings with them, as a Panel are few. Their support has enabled us to open many doors that would otherwise have been closed to us."

First of all, as I understand it, the Medical Advisory Panel existed as an entity before you arrived?

A. Correct.

Q. What do you understand by the reference to ignoring "their advice at our peril"?

A. I suppose it would refer to the fact that we could be setting up a direct conflict between patients and those who treat them.

Q. Was there also a --

A. But that's only a supposition.

Q. Was there also a sense that they were the clinicians and that they, somehow, would know best on matters of medicine and science?

A. That's certainly true. I used to tell them that, actually, the patients with haemophilia knew best because they lived with the condition 24 hours a day

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If you look at the top of the sentence, where it begins "There is fairly continual exchange" -- the word used is "exchange"; it isn't "flow" -- "of information and advice". So this suggests that advice was coming from the officers to the Panel as well as from the Panel to the officers. What advice do you think Mr Prothero had in mind that the officers were giving doctors?

A. I would have no idea, sir.

SIR BRIAN LANGSTAFF: Was it in reality one-way advice?

A. That would be my suspicion.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: Then if we can see that a number of years later -- that was 1982 -- a number of years later attempts were made to reorganise the Medical Advisory Panel and introduce proper terms of reference and make it more formal in terms of its structure. I think we don't need to look at the various iterations of different documents produced, but if we just go to HSOC0010470, please.

This is a document authored by you in November of 1991, and we can see it's headed "Medical Advisory Panel, Final Amended":

"The Haemophilia Society has had medical advisers since the inception of the Society. The size

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1 of the Panel has varied throughout the years and has
 2 consisted, to some extent at least, of 'favoured'
 3 Reference Centre Directors plus, more recently, other
 4 Centre Directors."
 5 Now just pausing there, you used the adjective
 6 "favoured" put it in speech marks there. What did you
 7 mean by that?
 8 A. I think I meant well known, long-serving. Of course
 9 I wrote it not realising I'd be asked questions at the
 10 Blood Inquiry today of course.
 11 Q. I mean, the sense it gives is that there were those
 12 who had a particularly close relationship with the
 13 Society and they tended to serve on the Panel, and the
 14 Panel's membership was, therefore, perhaps not as wide
 15 as it might otherwise have been. Is that fair?
 16 A. That's fair. That's fair.
 17 Q. And then --
 18 A. Again, it was the rather like The Haemophilia Society
 19 when I came. It was a very inbred organisation, with
 20 a group of people who had been around for a very long
 21 time together, and the list of eight people listed
 22 below kind of summarises the situation with the
 23 Medical Advisory Panel.
 24 Q. You go on to say in this document the Panel didn't
 25 meet until 1988 but I understand from your statement

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1 you thought the Society would gain more from
 2 a reorganised Panel?
 3 A. The Society was more interested in maintaining
 4 a friendly relationship with those powerful clinicians
 5 possibly.
 6 Q. Then if we go over the page we can see the proposed
 7 terms of reference that you had drawn up in 1991.
 8 "The ... Panel is established to advise the
 9 Executive Committee ... on matters affecting ...
 10 treatment and care", et cetera.
 11 Then this:
 12 "Members of the Medical Advisory Panel are
 13 expected to give the Executive Committee of the
 14 Society their best personal and unbiased opinion as
 15 distinct from reporting the policy of the Haemophilia
 16 Centre Directors' Organisation or any other body with
 17 which members of the MAP are singularly or
 18 collectively associated."
 19 Please again correct me if I'm wrong, but the
 20 inclusion of that by you in these draft terms of
 21 reference might be thought to suggest that that hadn't
 22 been what members of the Panel had always done; is
 23 that fair?
 24 A. That's more than fair, yes.
 25 Q. So you were concerned that you weren't getting the

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1 that you don't now think that's correct?
 2 A. That's not true. That's not true.
 3 Q. Then you say:
 4 "There have never been terms of reference for
 5 the Panel and this, along with the future direction of
 6 the Panel, is currently under consideration."
 7 You set out the current membership, and we'll
 8 look in a few minutes at the membership in the early
 9 80s, but then you say this:
 10 "The problems with the present position
 11 identified as the size of the Panel; the lack to terms
 12 of reference; the inability of the Panel members to
 13 adjust to an advisory role; the inability of the
 14 Society to capitalise on the valuable resource
 15 available to it, etc."
 16 Size of the Panel, did you think it was too
 17 large or too small?
 18 A. Too large.
 19 Q. A lack of terms of reference I think probably speaks
 20 for itself but what did you mean of the inability of
 21 Panel members to adjust to an advisory role?
 22 A. I think they were always defending the position of the
 23 HCDO rather than advising, there being a difference.
 24 Q. Then the last phrase, the inability of the Society to
 25 capitalise on the valuable resource, does that reflect

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1 best personal and unbiased opinion? Is that right?
 2 A. Indeed.
 3 Q. Then you go on, I won't go through all of it but
 4 point 4 is there will be a combined meeting with the
 5 Medical Advisory Panel twice a year, so a more formal
 6 structure:
 7 "Individual members ... [might] be asked for
 8 specific advice on other occasions ...
 9 "Individual members ... would be expected to
 10 keep the Society informed of developments in their
 11 specific areas of interest."
 12 Then we can see at 8:
 13 "The terms of appointment of each panel member
 14 will be for one year only and appointments will be
 15 made at the AGM of the Society."
 16 Is this right, a number of Panel members had
 17 been on the Panel for many years?
 18 A. Indeed, yes.
 19 Q. We can take that document down. Thank you, Soumik.
 20 When you arrived and in the early part of the
 21 1980s who had chosen members of the Panel? Do you
 22 know? How had they been appointed?
 23 A. I honestly do not know but I suspect seniority had
 24 something to do with it.
 25 Q. Do you know --

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- 1 A. Sorry, seniority and the numbers of patients they had
2 in their centres, yes.
- 3 Q. Would that lead to, as it were, a bias in favour of
4 Reference Centre Directors who would be the most
5 senior, larger centres?
- 6 A. Indeed. This was the constant problem, that the only
7 source of information, both from members of the
8 Executive Committee and from Medical Advisory Panel
9 members, related to reference centres and not to the
10 small centre in Plymouth, say.
- 11 Q. Do you know whether Medical Advisory Panel members,
12 either before their appointment or at any time
13 afterwards, were questioned about whether they had any
14 conflicts of interest? For example, whether had
15 associations with or funding from pharmaceutical
16 companies?
- 17 A. That's a terribly modern concept, of course, but no,
18 I don't think that ever arose.
- 19 Q. Was there any remuneration for members of the Medical
20 Advisory Panel?
- 21 A. None whatsoever. I think there was a reference there
22 in the document you just showed of refunding travel
23 costs or something.
- 24 Q. Then if we just look at the membership in the course
25 of the first half of the 1980s, Soumik, if we could go

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- 1 year; is that right?
- 2 A. Correct.
- 3 Q. If we just look at the second page, we can see, bottom
4 of the page, the membership of the Medical Advisory
5 Panel. So this is -- by the end of 1981 we've had
6 some slight changes of membership. We've got
7 Professor Bloom, Dr Colvin, Dr Forbes,
8 Professor Hardisty, Dr Jones, Dr Mayne Dr Rizza and
9 Dr Tuddenham.
- 10 A. Yes.
- 11 Q. Then if we look at HSOC0019918_035, please, Soumik,
12 this is minutes of a meeting of the council of The
13 Haemophilia Society in April 1982, and it just tells
14 us a little more about the appointment of additional
15 members to the Panel. So if we go to the second page,
16 please, and if we look at the second half of the page,
17 under the heading "Appointment of Medical Advisory
18 Panel":
- 19 "Mr Polton reported that following the March
20 meeting of the Council he had consulted with
21 Professor Bloom and, upon receiving his approval, had
22 approached Drs Colvin, Mayne and Tuddenham to
23 invite them to become members of the Medical Advisory
24 Panel."
- 25 Then we get the enlarged membership that we

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- 1 please to HSOC0019918_027, please. This is
2 an Executive Committee meeting from April 1980, so
3 it's obviously the year before you arrive. If we go
4 to the second page, we can see about halfway down the
5 page, point 5, "Appointment of Medical Advisory
6 Panel", and we can see who, at that stage, constitutes
7 the Panel: Dr Biggs, Dr Bloom, Dr Davies,
8 Professor Hardisty, Dr Jones and Dr Rizza, and then:
9 "Professor Ingram, who has recently retired
10 from St Thomas' Hospital, has agreed to be re-elected
11 on the understanding that he will give advice only on
12 general matters.
13 "Council agreed unanimously on the re-election
14 of the above Medical Panel."
15 So it appears that the process of re-electing
16 them, as it were, goes through fairly
17 straightforwardly on the nod, as it were?
- 18 A. Indeed. I suppose Dr Jones was the new boy on the
19 block in those days.
- 20 Q. Yes, although a Reference Centre Director as well?
- 21 A. Yes, yes.
- 22 Q. Then if we go, please, to HSOC0019508, please, Soumik.
23 This is the 1981 annual report. Mr Watters, this, as
24 I understand it, was a document that would be drawn up
25 at the end of the year or the beginning of the next

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- 1 just saw.
- 2 Can you assist with this: why was
3 Professor Bloom being consulted and asked to give his
4 approval to the Society's appointment of the members
5 to the Panel?
- 6 A. Well, I suppose, as chair of the HCDO, he would know
7 whether the people concerned would be reliable,
8 informed MAP members.
- 9 Q. Was there, do you think, a risk that by going through
10 the appointment process in that way, seeking the
11 approval of Professor Bloom, that you might exclude
12 those who had a different view or might be interested
13 in challenging the views of the established directors?
- 14 A. Nothing wrong with nepotism as long as you keep it
15 within the family, really.
- 16 Q. Was that your sense; that in terms of the Medical
17 Advisory Panel it was nepotistic, it reflected largely
18 the direction of the Reference Centre Directors?
- 19 A. Correct, yes.
- 20 MS RICHARDS: Sir, I note the time 11.15. Is this
21 a convenient point at which to break?
- 22 SIR BRIAN LANGSTAFF: Yes, it is, but just a couple of
23 questions of my own if I may.
- 24 Following on from that last question and
25 answer, you told us earlier that the Executive

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1 Committee of the Board of Trustees were largely --
 2 entirely, I think -- people who, if they had
 3 haemophilia, were treated in the big centres such as
 4 London. So presumably the selection of those to
 5 nominate for the MAP may have reflected their own
 6 relationships?
 7 **A.** Indeed, sir, yes.
 8 **SIR BRIAN LANGSTAFF:** You told me earlier that they
 9 were -- if a new trustee was wanted, there was
 10 a process of nomination. Who did the nominating?
 11 **A.** The membership.
 12 **SIR BRIAN LANGSTAFF:** The membership.
 13 **A.** Nomination forms were sent to the entire membership.
 14 They had to get the consent of the person they were
 15 proposing and -- a proposer and a seconder, and they
 16 just went on the slate.
 17 **SIR BRIAN LANGSTAFF:** Who were the proposer and seconder?
 18 Were they traditionally or usually members of the
 19 executive cell?
 20 **A.** Not necessarily. It could be a local group proposing
 21 someone and they would be from the local group
 22 committee possibly.
 23 **SIR BRIAN LANGSTAFF:** Thank you.
 24 **A.** Yes.
 25 **SIR BRIAN LANGSTAFF:** Yes, that's all that I ask.

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1 (11.19 am)
 2 (A short break)
 3 (11.45 am)
 4 **SIR BRIAN LANGSTAFF:** Ms Richards?
 5 **MS RICHARDS:** Mr Watters -- I can't hear or see Mr Watters
 6 at the moment.
 7 **A.** I'm here.
 8 **Q.** Great. You just disappeared off my screen,
 9 Mr Watters. Just still on the topic of the Medical
 10 Advisory Panel for a few more questions, Mr Watters,
 11 do you recall in the course of the 1980s any occasions
 12 in which the Society sought medical advice from
 13 clinicians who were not members of the Medical
 14 Advisory Panel?
 15 **A.** I don't have any independent recollection of anything
 16 like that.
 17 **Q.** Do you know whether written records of advice given by
 18 the Panel were routinely kept?
 19 **A.** Minutes were kept of all MAP meetings.
 20 **Q.** I'm not sure whether we've seen much by way of minutes
 21 of MAP meetings. In the 1980s, you would have
 22 expected such meetings as took place with the Panel to
 23 have been minuted, would you?
 24 **A.** I would, yes.
 25 **Q.** We can perhaps make further investigations in that

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1 **A.** I just felt that was a reasonably open process,
 2 actually.
 3 **SIR BRIAN LANGSTAFF:** Yes, well, I see that.
 4 We'll take a break now until 11.45. Will that
 5 be long enough for you to have a cup of coffee and
 6 break?
 7 **A.** That will be wonderful, thank you.
 8 **SIR BRIAN LANGSTAFF:** Well, let's do that. 11.45.
 9 **MS RICHARDS:** Sir, Mr Watters, being in the middle of his
 10 evidence still, will require the usual advice.
 11 **SIR BRIAN LANGSTAFF:** I had better tell you, as I tell all
 12 witnesses, you've probably heard me do this when you
 13 have been watching some of our earlier
 14 proceedings: you're giving evidence, you are on oath;
 15 you must not talk to anyone, whoever they are, about
 16 the evidence you have given or the evidence you think
 17 you might yet be asked to give.
 18 **A.** Yes.
 19 **SIR BRIAN LANGSTAFF:** Anything else of course you can chat
 20 about. So it doesn't stop you talking to those in the
 21 house.
 22 **A.** I will go talk to my dog.
 23 **SIR BRIAN LANGSTAFF:** I shall see you at 11.45.
 24 **A.** Thank you.
 25 **SIR BRIAN LANGSTAFF:** Thank you very much.

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1 regard.
 2 Then, did you have a sense, again I'm
 3 concentrating here on the 1980s, Mr Watters, of
 4 whether other members of the Panel felt able to
 5 disagree with Professor Bloom or whether his
 6 decision-making was the major influence on the Medical
 7 Advisory Panel?
 8 **A.** I mean, as I recall meetings of the Medical Advisory
 9 Panel and as I learnt from meetings of the Haemophilia
 10 Centre Directors Organisation, there appeared to be
 11 very little disagreement with Professor Bloom's line.
 12 **Q.** In terms of the meetings of the UKHCDO, you attended
 13 them, I think, in the course of the 1980s.
 14 **A.** Well, I would have attended the one a year, I think.
 15 **Q.** Yes. But did you receive any impression as to the way
 16 in which the UKHCDO was structured and how it
 17 operated?
 18 **A.** Very little and, of course, we never received the
 19 minutes of the meetings to the best of my recall.
 20 **Q.** Prior to the steps that you took in 1991 to introduce
 21 terms of reference and a greater degree of structure
 22 to the Medical Advisory Panel, had any earlier steps
 23 been taken to address the kind of concerns that you're
 24 identifying?
 25 **A.** No formal steps, to the best of my recall.

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1 Q. Can you assist us with why that was, why this issue
2 was not tackled earlier?
3 A. I think there were too many other pressing matters,
4 really.
5 Q. Would you agree with this, Mr Watters, that by taking
6 advice only from the senior members of UKHCDO, was the
7 Society effectively disabling itself from scrutinising
8 the treatment policies and recommendations that were
9 being made by UKHCDO?
10 A. With the benefit of the hindsight, I would certainly
11 agree with that.
12 Q. You've made reference in your statement to
13 an awareness that younger haematologists might have
14 had a different approach.
15 A. Indeed, yes.
16 Q. Again, with hindsight, do you think that the Society
17 should, really from the outset, have looked to have
18 a more balanced membership of the Medical Advisory
19 Panel, precisely so it could hear disagreement and
20 dissent?
21 A. I do indeed and that takes me back to my thoughts
22 about the Executive Committee being made up of people
23 who attended the big centres, therefore only the big
24 boys got in on the act really, whereas there were
25 rising stars like the then very young Dr Mark Winter,

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1 I can't recall specifically what might have been in my
2 mind on 8 August 1988.
3 Q. Because what you have just said to us in your earlier
4 answers is you think it would be healthy for the
5 Society to have a range of different opinions being
6 conveyed to it.
7 A. Ah, yes, I do think that would be the case but, at the
8 end of the day, we would be striving to reach
9 a consensus view --
10 Q. Okay.
11 A. -- having listened to all views.
12 Q. Then in your statement you've referred to or you've
13 said this: if the Society was repeatedly phoned by
14 members asking similar questions, so if there was
15 a particular topic of concern amongst members, you
16 would seek permission to discuss those issues with the
17 Medical Advisory Panel.
18 Can you recall whether the risk of infection
19 from blood products was a common topic raised in
20 questions by members?
21 A. Sorry, I lost track in the middle of your question.
22 Q. Was the risk of infection from blood products a topic
23 that was commonly raised by phone or letter by
24 individual members with you?
25 A. At what stage?

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1 for instance, who was -- had views that weren't always
2 surfaced.
3 Q. Would it be fair to say that the Society was too
4 trusting of the advice that it was given by members of
5 the Medical Advisory Panel, in your view?
6 A. Certainly, with the benefit of hindsight, that is the
7 case.
8 Q. I wanted to ask you about something you said in
9 a letter, at least I think it's from you, HSOC0011023.
10 Yes, it's letter from you to Dr Ludlam in 1988. We
11 can see that you were writing to Dr Ludlam on
12 8 August 1988. The context was an invitation to him
13 to attend a meeting of the Medical Advisory Panel and
14 you talk in the second main paragraph about the
15 Executive Committee wanting the Medical Advisory Panel
16 to play, effectively, a bigger role in the life of the
17 Society.
18 Halfway through the paragraph you say this:
19 "I think it is essential that the MAP be
20 consulted on, for instance, treatment and blood
21 products, especially since it is in everyone's
22 interest that we should all 'say the same thing'."
23 What did you mean by that, Mr Watters?
24 A. I think that there was a danger of differing advice
25 from the Society and the Medical Advisory Panel.

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1 Q. At the moment, if we talk about pre-AIDS.
2 A. It was not a common topic pre-AIDS.
3 Q. Did it then become one as the 1980s continued?
4 A. Oh, but of course.
5 Q. We can take the document down, thank you, Soumik.
6 You have observed also in your statement that
7 there was no direct link between the Medical Advisory
8 Panel and the Blood Products Subcommittee. Do you
9 think that there should have been a link?
10 A. Well, I suppose the link was Ken Milne who would
11 normally attend meetings of the Medical Advisory Panel
12 if his other work arrangements allowed him to. But
13 there was nothing formalised in there that said he
14 would and that's the difference between practice and
15 policy.
16 Q. I want to come on to ask you about the Society's
17 position and policy in relation to blood products in
18 the early part of the 1980s. So this is still
19 pre-AIDS.
20 When you joined the Society in 1981, were you
21 aware or did you become aware that the Society had
22 voiced concerns over a number of years about
23 insufficient supplies of concentrates?
24 A. Oh, yes. Oh, yes.
25 Q. I want to ask you about a couple of documents. The

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first is HSOC0022906. This is a Bulletin from 1981, so it's around the time that you're joining the Society and if we look in the left-hand column, bottom half of the page, we can see, and this is taken from, I think, the annual report:

"Another central concern of the Executive has been the issue of blood products. A Blood Products Subcommittee has been formed to look into this subject and promises to be a very valuable addition to the Executive.

"Towards the end of the year increasing concern was felt at the unsatisfactory situation regarding supply of Factor VIII concentrate. The main causes for concern were:

"1. The possibility of [BPL], where most of Britain's Concentrate is produced, being placed under commercial management.

"2. Inadequate supplies of Concentrate to meet present and future demand.

"3. Increasing reliance on imported commercial material, contrary to the World Health Organisation policy that countries should be self-sufficient in blood products, and with the possibility of greater risk of hepatitis infection."

Then it continues:

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Mr Milne's role in the way you described?

A. It was essentially Mr Milne's role in the way I've described and I think that could have been put more accurately.

Q. Then if we go to one other document, this is from just before you arrive, Mr Watters. Soumik, it's HSOC0019919_022, please. These are minutes of the Executive Committee on 9 December 1980. So a couple of months before you took up your post. If we go to the second page, please, and we look at the first half of the page, the long paragraph beginning "Mr Prothero reported", if we go about ten or so lines down it says:

"Mr Prothero reported on a new machine that had been developed by Travenol at a cost of 1 million dollars. This would enable an increase in the production of Factor VIII concentrate to be made with improved quality. Mr Prothero and Mr Polton had lunch with some of the chief personnel of Travenol Europe. Travenol is the largest supplier of plastic bags and equipment generally to the [BTS]."

Then it says this:

"Mr Tanner said present developments makes it necessary for the Society to make some policy decisions in relation to commercial products."

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"Although the DHSS has decided not to involve commercial organisations in managing the BPL, the other problems are not yet resolved, although the DHSS has agreed to embark on the first stage of an expansion programme at the BPL. It is intended to monitor the situation much more closely than in the past, and a new subcommittee of the Executive Committee has been set up to do this, in co-operation with the Haemophilia Centre Directors, and to assist in pressing the DHSS to provide adequate supplies of Factor VIII."

Now, is that an accurate summary of the Society's concerns and policy in relation to the issue of factor concentrates and supply at the time you joined the Society?

A. Yes, I would say it was, in as far as I remember things terribly clearly from 40 years ago.

Q. We can see the reference at the top of the second column to the subcommittee, that's the Blood Products Subcommittee, having been set up to monitor the situation in co-operation with the Haemophilia Centre Directors. That might suggest there was some kind of direct link between the Haemophilia Centre Directors, or UKHCDO, and the Blood Products Subcommittee. Do you know if any formal link or was it essentially

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Then there is:

"Mr Polton stressed the need to keep in close contact with Travenol pointing out that one of the directors was on a DHSS Committee on blood products."

Can you assist with this, Mr Watters: the reference to Mr Tanner saying "necessary for the Society to make some policy decisions in relation to commercial products", do you know what that might refer to?

A. I wouldn't know what was in Mr Tanner's mind when he said that. I can, however, surmise he was talking about commercial products as opposed to British products.

Q. In terms of having to make policy decisions, you don't know specifically what that refers to?

A. No, no.

Q. If we then turn to your first or what I think was probably your first Executive Committee meeting, possibly your second, it's HSOC00109919_026. Sorry, I've given you the wrong -- Soumik, my apologies, I added a zero. HSOC0019919_026.

So if we look at the top of the page, we can see it's the minutes of a meeting of the Executive Committee on 5 March 1981, and those present include you. So this would either have been your first or

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1 second Executive Committee meeting.
 2 If we go down to the bottom of the page, we can
 3 see there under the heading "Blood Products
 4 Sub-Committee", there's a report from, I think,
 5 Mr Milne and Mr Prothero. Before we look at the
 6 detail of it, was the Blood Products Sub-Committee
 7 minuted, because I don't think we've seen minutes as
 8 such. We see reports to the Executive Committee.
 9 A. My recall would have been that they should have been
 10 minuted. Whether they just took notes and reported to
 11 the Executive doesn't come back to my mind at this
 12 time.
 13 Q. Then I just want to get a sense of whether this is
 14 a sort of typical Executive Committee meeting. So
 15 we've got a report from the Blood Products
 16 Sub-Committee and a reference to the committee
 17 gathering information and statistics for a meeting
 18 with the minister. Then if we go over the page, at
 19 the very top of the page there's a reference to your
 20 new role and your job title of co-ordinator.
 21 We can then see a "Group Seminar", there's
 22 a report on the group seminar, and interest in the
 23 process and issue explored about seeking funding from
 24 pharmaceutical companies.
 25 Then we can see there's the "Group Liaison

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1 A. Yes, yes.
 2 Q. You have helped us with an understanding of the way in
 3 which you believe the Medical Advisory Panel operated.
 4 In terms of the Executive Committee, when there were
 5 matters that had to be decided as opposed to just
 6 noting reports, to what extent was there disagreement?
 7 Were people able on the Executive Committee freely to
 8 speak their mind and disagree with what was being
 9 suggested?
 10 A. Oh, yes. In fact, very soon after my appointment we
 11 had two members of the Executive Committee resign
 12 dramatically in a meeting in opposition to the
 13 establishment of my post. It was quite dramatic.
 14 I can recall chairs being overturned and all sorts.
 15 Q. When you took up your post in 1981, had you seen or
 16 been told of the 1975 World in Action documentary
 17 which looked at issues of risk associated with
 18 sourcing plasma for factor concentrates in the States?
 19 A. I wasn't aware of it when I went into the post but
 20 I soon became aware of it.
 21 Q. How did The Haemophilia Society, again it is talking
 22 here 1981/1982, how did it keep abreast of developing
 23 knowledge about risks? How did it monitor the safety
 24 of concentrates?
 25 A. Well, as we've already established, the Society was

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1 Officer's Report" at point 6, towards the bottom half
 2 of the page. Was there someone then whose role it was
 3 to liaise with the local groups and report back to the
 4 Executive Committee?
 5 A. That was Dr Kuttner's role, but I noticed that he
 6 ceased that function at a certain stage and it clearly
 7 ended up on my desk as well.
 8 Q. Then if we go to the next page, we can see there's
 9 a treasurer's report and then there's the "Honorary
 10 Secretary's Report", that's about grants, and then we
 11 can see "European Liaison Officer's Report & WFH
 12 Matters", and then there's a discussion about how to
 13 facilitate attendance at the World Federation of
 14 Haemophilia conference in Costa Rica.
 15 A. Yes.
 16 Q. It sounds from the title, "European Liaison Officer",
 17 as though there was somebody, a member of the
 18 Executive Committee, whose function it was to liaise
 19 with Haemophilia Societies in other European nations;
 20 is that correct?
 21 A. That's correct.
 22 Q. So is this a fairly typical Executive Committee
 23 process? There are reports made by subcommittees and
 24 members with particular responsibilities to the
 25 Executive Committee for them to reach decisions?

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1 a very small and vulnerable organisation and we had to
 2 rely on all sorts of people for information and
 3 advice, medical journals, if we happened to have time
 4 to read them, friendly doctors who may tell us things.
 5 But I'm afraid we didn't have the resources to be
 6 monitoring everything and every bit of news media.
 7 Q. We can see quite a few references in Executive
 8 Committee meetings of reports from the Blood Products
 9 Sub-Committee of meetings with pharmaceutical
 10 companies. Is it fair to say that pharmaceutical
 11 companies were one source of the information that the
 12 Executive Committee had available to it through the
 13 mechanism of the Blood Products Sub-Committee?
 14 A. That would have been one source but only one source,
 15 yes. I mean, we also -- particularly we had close
 16 relationships with people like Andy Veitch, who was
 17 the medical correspondent of The Guardian at that
 18 time, who was always very helpful and interested in
 19 our cause, as well as close links with The Sunday
 20 Times, who carried many articles on the compensation
 21 issues, and they were very good at keeping us informed
 22 as well.
 23 So we were never relying on one source of
 24 information. Would that we had been able to afford
 25 a full-time research officer who could have kept an

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1 eye on all those things, but I say that with the
2 benefit of hindsight of course.
3 **Q.** I just want to get a sense of what the sources of
4 information would have been. You have identified
5 a possibility of journalistic information being
6 provided to the Society, pharmaceutical companies.
7 You've described already the regular meetings with
8 civil servants at the DHSS. We've obviously got the
9 Medical Advisory Panel and UKHCDO, which we've
10 discussed.

11 Would that cover the principal sources of
12 information that the Society would have had at that
13 time to enable it to reach an informed view about
14 risks?

15 **A.** Did you mention HCDO in that list?

16 **Q.** Yes.

17 **A.** Yes, yes. That would be it.

18 Of course, we always had to filter that
19 information, because all those parties, especially the
20 Department of Health, HCDO and things, they only told
21 us what they wanted us to know, and that was why it
22 was so important to have the journalistic input as
23 well.

24 **SIR BRIAN LANGSTAFF:** You would add there, would you,
25 The Lancet and The BMJ, if you had time?

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1 alternatives there: either mild or serious.

2 **A.** Mild, mild.

3 **SIR BRIAN LANGSTAFF:** That's what you were trying to say
4 but just for the sake of the record, so it's clear.

5 **A.** Indeed, many years later when I went to work for
6 another organisation, the Primary Immunodeficiency
7 Association, there was an outbreak of hepatitis C
8 because of it then being classified, and again we were
9 told it was a very mild condition, it was a benign
10 condition that wouldn't affect too many people too
11 badly. I have to add that that infection was due to
12 a break down in manufacturing process in the
13 United States, created by CDC or someone like that,
14 which was very quickly put right.

15 **MS RICHARDS:** You've told us that you don't think that the
16 Society received copies of minutes of UKHCDO meetings.
17 Did the Society receive copies of anything produced by
18 the UKHCDO's Hepatitis Working Party, any of its
19 reports or studies?

20 **A.** I think not. I don't recall.

21 **Q.** Do you recall, in the course of perhaps the first half
22 of the 1980s, or indeed later into the 1980s, whether
23 the Society had any particular the policies or
24 concerns about storage of blood samples from
25 haemophilia patients?

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1 **A.** Indeed if we had time to read it, yes.

2 **MS RICHARDS:** Again, when you started in 1981 and over the
3 next couple of years, do you recall whether the risk
4 of hepatitis was something that was prominent in the
5 Society's thinking?

6 **A.** Oh, yes. I mean, all that featured in the Society's
7 overarching concern that the UK should become
8 self-sufficient in blood products, following the
9 promise of Dr David Owen in 1974/5, yes.

10 **Q.** Can you recall anything about what the Society's
11 understanding was, or your understanding was, in
12 relation to non-A, non-B hepatitis in the early 1980s?

13 **A.** Could you be more specific about the question?

14 **Q.** Absolutely, Mr Watters. Did you or your colleagues,
15 as far as you can recall, understand non-A, non-B
16 hepatitis, what we now know as hepatitis C, to be
17 a mild, benign condition or a serious condition?

18 **A.** That was what we were told at the time and I guess
19 that was possibly based on the knowledge at the time,
20 which we see reflected very clearly in the present
21 Covid-19 instance, where hopefully not in 40 years
22 time there will be another public inquiry into what
23 went wrong there.

24 **Q.** Well, you say that was what you were told --

25 **SIR BRIAN LANGSTAFF:** Just a moment, you were given two

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1 **A.** We did indeed because it came to our attention that
2 the stored samples were being tested retrospectively
3 and without consent from the patients whose samples
4 they were.

5 **Q.** So is this right, that wasn't something that you were
6 aware of in the first half of the 1980s, it came to
7 light through the process of testing people for HIV?

8 **A.** Correct.

9 **Q.** Now, I want to look at some details of ministerial
10 meetings in 1981/1982. If we go first of all to
11 HSOC0020339, please. We can see here a document
12 headed "Briefing paper for meeting with Dr Gerard
13 Vaughan -- 21st October 1981":

14 "Attached to this brief outline is the updated
15 paper which has been discussed in the Blood Products
16 Sub-committee."

17 I'm afraid we don't have to hand the updated
18 paper but we have the outline:

19 "Supply of Factor VIII."

20 Then there's reference to Dr David Owen's
21 statement about self-sufficiency, and then this
22 document says:

23 "This expectation has not been realised and
24 estimates for total requirement of Factor VIII have
25 now doubled to 100 million units.

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"Our prime question is: is self-sufficiency still departmental policy."

Then "If 'yes'", there are a series of questions there set out about how it's going to be achieved and then we can just see from the second page that the second topic for the ministerial meeting relates to prescription charges.

I'm just going to show you that and then show you a document, Mr Watters, relating to the meeting itself. If we could then go to DHSC0002211_062, and if we go to the second page, we look at the top half of the page we can see it's:

"Note of a meeting between MS(H) [that's the Minister of State for Health] and representatives of The Haemophilia Society on Wednesday 21 October 1981.

"Present: [Minister of State for Health] Mr Godfrey."

Then from The Haemophilia Society, five people present, including you, Mr Watters, and then:

"Supply of Factor VIII.

"The Haemophilia Society's representatives were concerned that the NHS was so reliant upon expensive imported blood products and feared that cuts in NHS expenditure might result in health authorities refusing to supply Factor VIII to haemophiliacs.

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ministers would always meet a group of patient representatives, and we were assured that the door we had come to push on we must not push too hard because it was already open and steps were well advanced to make sure that the United Kingdom became self-sufficient in blood products, and all this came before we had really said why we had come and what we wanted to talk about, and we went away thinking "Hey, what does this guy know that we don't know? What's triggered this sudden change of approach?" But, yes, this was the meeting.

Q. So you understood there to be in this meeting -- we saw from the briefing paper you had intended to ask the question is it still the Government's policy that there should be self-sufficiency and, is this right, that the minister was saying that the Government did support that objective?

A. Yes, yes.

Q. Then there's a reference here to there being an upgrading programme of BPL. Do you know whether that was something the Society knew about before the meeting or was that information it gained during the meeting?

A. I can't recall.

Q. This is obviously only a note, not detailed minutes or

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MS(H) assured the Society of the Government's support for the principle of self-sufficiency in blood products though he stressed that this had to be a long-term aim as the present Blood Products Laboratory at Elstree was not able to manufacture sufficient Factor VIII to obviate the need to import blood products. MS(H) reported that the Laboratory's current upgrading programme would double Factor VIII production to 30 million international units by the end of 1982. Planning of the new Laboratory had begun. It was too early at this stage to say what its capacity would be or when it would be fully commissioned."

Then 2:

"The Haemophilia Society accepted that self-sufficiency should only be aimed for if it could be shown to be economic to do so."

Can I ask you, first of all, Mr Watters, what recollection you have of this meeting because I think you talked about certainly a meeting with Dr Vaughan in your statement and I think it may have been this one.

A. I remember the meeting very well because we were totally taken by surprise. We were received by Gerard Vaughan in a very warm way, not the way

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a detailed account of the meeting, but there's obviously concern being expressed about problems with supply of Factor VIII for haemophiliacs. There's no express reference here to issues about risk, risks of infection or hepatitis.

Do you recall whether that was discussed in the meeting with the minister at all?

A. It was discussed in the meeting and, as for point 2 of the note of the meeting, I certainly have no recollection whatsoever of The Haemophilia Society ever accepting that self-sufficiency should only be aimed for if it could be shown to be economic to do so. Our interest was never based on economics; it was based entirely on the health of people with haemophilia.

You possibly saw me smile when the slide came up. I wondered if it was the same meeting for quite some time but I'm now satisfied it was.

Q. You've anticipated what my next question was going to be, which was about point 2. Just going back to my earlier question, you recall risks of hepatitis were discussed in the meeting you think?

A. They would have been discussed, yes.

Q. Then we can see the letter -- so point 4 on this note records the Society asking if the minister would write

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confirming plans to increase the supply of Factor VIII produced by BPL.

Then we can see the letter that was written by the minister at RLIT0001226.

We can see it's a letter of 30 October 1981 from Dr Gerard Vaughan, and if we look at the second paragraph he says:

"I appreciate your Society's concern about the extent to which the NHS relies upon commercial blood products. As I told you, the upgrading programme being carried out at the [BPL] ... will, at present yields, enable the Laboratory to double its output of Factor VIII ... by the end of 1982. While this will not eliminate the need for commercial products, it represents a major step forward in NHS production of this vital material."

Then he adds this:

"I also said we plan to replace the existing [BPL] within the next few years ..."

He goes on to talk about that in fairly general terms, and then says this:

"Although I endorse the principle of self-sufficiency in blood products, it is only realistic to recognise that demand for Factor VIII is constantly increasing, and that self-sufficiency is

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accelerator?

A. Yes, yes.

Q. That was because you -- this is what you say in your statement -- you thought the department may have had some sense there was going to be a potential for a major crisis with blood products.

A. That only became clear with hindsight but ...

Q. The 1982 meeting with Mr Vaughan we can see reflected in some Executive Committee minutes, so if we go to HSOC0029476_015, if we look at the top part of the page to start with, we can see it's a meeting of the Executive Committee on 9 September of 1982.

Then if we go to the second page, please, Soumik, and we look at the top of the second page, we can see:

"Mr Milne reported that he and the Co-ordinator ..."

So that's you and Mr Milne.

"... had met with representatives of the DHSS on Tuesday, 7th September and that they had discussed the development of the Blood Products Laboratory at Elstree; prescription charges; Mobility Allowance possible DHSS funding."

Then it says this:

"In discussion the Executive Committee accepted

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not a goal we can achieve in the immediate future."

Then he talks about the work of the Society and suggests it may be useful to meet again.

Does that accurately reflect your recollection of what the minister said at the meeting?

A. I think there was much greater emphasis at the meeting on actually achieving the self-sufficiency than is implied either in the note or in that letter. I think the Civil Service may have tweaked the minister's enthusiasms before committing it to paper.

Q. So is this right, your impression of the meeting was there was a more enthusiastic or unqualified support for achieving self-sufficiency than one sees reflected in the written materials?

A. Yes and, of course, at that time we were not particularly aware of HIV, I don't think, but the Department of Health clearly were, and I think that shock had given them a little kick in the pants, as it were.

Q. Yes, the way you put it in your statement -- and it's right to say that you had another meeting, I think, in 1982, and we'll look at that in a moment --

A. Yes.

Q. -- but you say that your sense was that the department had reached a decision to put their foot on the

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that it would be unwise for the time being to pursue further the question of prescription charge exemption ..."

Then there's a reference to mobility allowance and a possible funding.

So it would appear that that meeting may have been more just an update on the work because there's no major revelation set out in this account.

A. No.

Q. Do you have any independent recollection of this further meeting with Dr Gerard Vaughan or whoever the minister was?

A. None at all. I don't even know that it was with Dr Gerard Vaughan. It says "representatives of the DHSS", which could imply it was civil servants that we met with.

Q. Yes, the heading is "Meeting with the Minister", but you're right, it then says, "representatives of the DHSS". You can't recall which it was?

A. No, no.

Q. We can take that down, thank you.

Do you know, Mr Watters, whether the Society or the Blood Products Committee, either prior to your arrival or in the course of the first half of the 80s, made any attempts to influence Government

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1 decision-making on the licensing of blood products?
 2 A. I've no recall.
 3 Q. And then in your --
 4 A. If you had a document it may prompt me.
 5 Q. No, no, no, it was a general question, Mr Watters. No
 6 specific document.
 7 You then -- in your statement, when you talk
 8 about self-sufficiency in your statement, you have
 9 said this -- perhaps we will put it up on screen for
 10 the benefit of those watching.
 11 It's WITN3429001, and if we go to page 68,
 12 please. Four pages on.
 13 In paragraph 148 you say this. You were asked
 14 whether the Society had received assurances about
 15 self-sufficiency. You have referred to Dr Owen's
 16 assurance, and then you speak about the meeting with
 17 Dr Gerard Vaughan, and you have given us your account
 18 of that.
 19 Then you say this:
 20 "That was a complete turnaround by any
 21 Government since Dr David Owen left his post as
 22 Secretary of State for Health. After Dr David Owen
 23 had left his post the Government had essentially gone
 24 back on what had been pledged. I think people stopped
 25 just short of saying 'no, we're not going to go for

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1 Q. So that's part of the reason for the surprise reaction
 2 of those attending this meeting?
 3 A. Indeed, yes.
 4 Q. We can take that down, thank you.
 5 Can you recall the extent to which within the
 6 Society, again prior to the AIDS coming on the scene,
 7 so really we're talking here '81/'82, or '81 and the
 8 first half of '82, can you recall the extent to which,
 9 within the Society, there were discussions about
 10 dangers associated with large pool sizes of donations?
 11 A. Yes, I can remember the discussions but I can't
 12 remember the details.
 13 Q. Were there discussions about the relative safety of
 14 NHS versus commercial concentrates?
 15 A. Yes, and NHS concentrates were seen as pure as the
 16 driven snow, really.
 17 Q. Can you recall in the first half of the 1980s whether
 18 there any discussions within the Society about sources
 19 of blood donations in the UK, in particular collection
 20 of blood from prisoners or military donors? Was that
 21 something the Society talked about?
 22 A. Not a lot but it was there in discussions and was seen
 23 as undesirable, the volunteer donor being the basis of
 24 safety.
 25 Q. So there was some awareness, is this the right way of

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1 self-sufficiency'. I think it simply dropped way down
 2 the priority list ..."
 3 Can I just ask you what's the basis for your
 4 feeling, your sense that what you were being told by
 5 Dr Vaughan was a turnaround from the position since
 6 Dr Owen had left his post. Was that the reaction of
 7 your colleagues who had been there for longer or
 8 something else?
 9 A. Oh, yes, yes, yes. I mean, first of all, we got this
 10 sudden invitation out of the blue to go and meet
 11 Gerard Vaughan. That's not the way it normally works;
 12 you have normally got to beg for a meeting with
 13 a minister. And then for this sudden dramatic
 14 announcement that new money had been found to invest
 15 in BPL and that there were plans to build a new plant
 16 and everything else was just completely out of the
 17 blue. They had always said in the past that it made
 18 economic sense to use imported blood products from the
 19 United States and the benefits far outweighed the
 20 disadvantages and so on and so forth.
 21 Q. So is this right, in '81/'82, the Society's sense had
 22 been that the goal of self-sufficiency had effectively
 23 been abandoned, hence the briefing paper we saw where
 24 that question was going to be posed of the minister?
 25 A. Yes.

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1 putting it, there was some awareness within the
 2 Society that in the United Kingdom there were blood
 3 collections from prisoners and from military donors?
 4 A. Yes, yes.
 5 Q. Do you know whether that's something the Society ever
 6 made representations about to the Blood Transfusion
 7 Service or to the DHSS?
 8 A. I've got no recollection of that at all. It may well
 9 have been made even before I arrived on scene.
 10 Q. Now, in terms of how the Society then disseminated
 11 information to its members about, in particular, the
 12 risks associated with treatment, would The Bulletin
 13 have been the main way in which the Society
 14 communicated its understanding of risks to its
 15 members?
 16 A. Indeed, yes.
 17 Q. So there is The Bulletin, there are the roughly annual
 18 Group Seminar Proceedings, again we will come on to
 19 Haemofact in due course --
 20 A. I think we also had a residential conference in quite
 21 a few years but that may have been later.
 22 Q. So is it fair to say that if we, as an Inquiry, are
 23 looking to see what the Society was saying to its
 24 members about non-A, non-B hepatitis, The Bulletin is
 25 probably the best source?

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1 A. Oh, absolutely, yes. I can't recommend it as
2 a thoroughly reliable source but it would be the
3 source of any information that was there.
4 Q. Yes, it will tell us what, as a matter of fact, was
5 being said, even if it wasn't correct.
6 A. Yes.
7 Q. We'll just look at one example then of that. It's
8 BART0002327_001. We can see this is The Bulletin --
9 not sure where, I can't quite see the date on this at
10 the moment. I am pretty sure it is 1982.
11 A. We weren't good at dating publications.
12 Q. No, I think that's undoubtedly true. We can see the
13 Chairman is writing and he wishes all good wishes for
14 1982, which is how I'm giving it that date. If we go
15 to page 6, please?
16 SIR BRIAN LANGSTAFF: It does say 1982 at the top.
17 A. Oh, it does, yes.
18 MS RICHARDS: Thank you, sir. On my black and white
19 photocopy it doesn't come out at all but yes, thank
20 you.
21 SIR BRIAN LANGSTAFF: It's pretty faint on ours but you
22 can just see it.
23 MS RICHARDS: This is an article on page 6 of it, if we
24 zoom in on the right-hand column please, Soumik, the
25 article that begins "Jaundice cases show unexplained

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1 called hepatitis non-A non-B (because it is neither
2 one nor the other). This is known to be spreading in
3 the States, and there is speculation that it may have
4 arrived here."
5 Now, currently, as far as we can assess, this
6 is the first reference to non-A, non-B hepatitis in
7 the Society's Bulletins, although I've no doubt that
8 we'll be corrected if we're wrong in relation to that.
9 Does it surprise you that, as at 1982, all
10 that's being said about non-A, non-B hepatitis is that
11 there's speculation it may have arrived here?
12 A. No, not at all.
13 Q. Is it fair to say non-A, non-B hepatitis was not
14 something that was foremost in the Society's mind at
15 this time?
16 A. In 1981, possibly not.
17 Q. Is that in part because of the understanding you
18 referred to earlier that it was just a mild condition
19 and not something to be worried about?
20 A. Mild condition, yes.
21 Q. Is it fair to say that if members of the Society were
22 relying upon the Society for information about non-A,
23 non-B hepatitis there's relatively little information
24 they'd have received from the Society by the early
25 1980s?

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1 increase", and there's a reference there to
2 Andrew Veitch and then we can see at the bottom of his
3 article it says "With grateful acknowledgments to the
4 Editor of 'The Guardian', 5th August 1981". So do
5 I correctly understand this is effectively the
6 reproduction in The Bulletin of an article published
7 by one of the journalists you mentioned in The
8 Guardian.
9 A. Indeed, yes.
10 Q. We can see Mr Veitch saying:
11 "Figures released yesterday show that the
12 number of cases of infective jaundice in England and
13 Wales rose by 60 per cent to more than 5,000 last
14 years, and the 5-14 year-olds suffered most.
15 "The illness is commonly caused by one of the
16 hepatitis viruses."
17 Then there's a reference to hepatitis A and
18 then says this is on the decline.
19 Dame Sheila Sherlock at the Royal Free is recorded as
20 saying it's "out of keeping with trends all over the
21 world". Then it says:
22 "The rate of jaundice among children has been
23 falling for years, but last year it shot up ..."
24 Then it says this:
25 "One possible culprit is a third virus, simply

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1 A. As I understand it, there was very little information
2 to be had anyway but, yes, what you say is correct.
3 Q. You've said more generally in your statement about the
4 Society's publications that they were never intended
5 to replace the medical advice that patients were
6 entitled to receive from their clinicians. Is that
7 correct?
8 A. We said that particularly on Haemofact.
9 Q. But it is right to note, is it not, that The Bulletin
10 would contain articles written by clinicians?
11 A. Yes.
12 Q. What was done with The Bulletin? Was it sent by post
13 to the Society's members?
14 A. Oh, my goodness me, you bring back horrid memories of
15 an old Addressograph machine. The cards had to be
16 soaked in water and people's addresses typed in, then
17 they had to be dried and then they were put in
18 cartridges, and nine times out of ten, half of them
19 ended up flying all over the room and you had to check
20 very carefully to make sure that all the envelopes had
21 been printed. But, yes, The Bulletins were delivered
22 to the office. We addressed envelopes and stuffed
23 them and mailed them, putting a postage stamp of the
24 right value on each one, because we didn't even have
25 a franking machine in those days.

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1 Q. Now, The Bulletin had its own editor but he wasn't, as
2 I understand it, someone with any medical
3 qualifications himself?

4 A. Oh no, no. A member of the trustees, a patient.

5 Q. Was there any process of verification of what was
6 being said in articles in The Bulletin ever undertaken
7 or was it just a clinician had been asked or had
8 volunteered an article and it would be printed with no
9 further consideration?

10 A. If there was any doubt it would have been referred to
11 the Chairman of the Haemophilia Centre Directors
12 Organisation for an opinion. I can't recall whether
13 that ever happened or not.

14 Q. Bulletins we've discussed, Haemofact we'll come on to.
15 Group Seminar Proceedings: what happened with the
16 Group Seminar Proceedings publications? Were they
17 sent to every member or only those persons who had
18 attended a seminar?

19 A. No, every member.

20 Q. Executive Committee or council minutes, were those for
21 internal purposes only; they weren't sent to members?

22 A. I think council members got Executive Committee
23 minutes and Executive and council got their minutes.
24 It was really up to councils what they did with the
25 minutes when they got them. They were open to share

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1 clotting.

2 "The product ... has transformed the lives of
3 haemophiliacs ... Now it is being linked in America
4 with a devastating and mystifying disease ..."

5 Then it goes on to explain more about AIDS. So
6 that was the article on 16 January 1983.

7 You then sent it to Professor Bloom and asked
8 for further information, and I want to look at that
9 with you, please. It's BPLL0001351_071. We can see
10 on 19 January 1983 you wrote to Professor Bloom as
11 follows:

12 "The Reverend Alan Tanner has asked that
13 I write to you enclosing this article from The
14 Observer of Sunday 16 January. We are writing to you
15 in your capacity as Chairman of the Centre Directors
16 Meeting and our own Medical Advisory Panel to seek
17 some clarification on current thinking in the UK on
18 this matter which has, naturally, raised some anxiety
19 with calls coming from as far as away as The Hague!

20 "It would be most helpful to us if you could
21 offer guidance at this stage, with the possibility of
22 an early-date article for The Bulletin so that we can
23 keep our members in touch with the situation."

24 Now, can you recall, first of all, Mr Watters,
25 what you knew or what you understand the

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1 them with their committee, their membership or
2 whatever, yes.

3 Q. So those on the council who were the representatives
4 of the local groups could share them with their local
5 group members?

6 A. Yes.

7 Q. But the Society itself did not provide copies of the
8 Executive Committee or council minutes to its members?

9 A. No. Anything significant would be reported in The
10 Bulletin itself, like research grants awarded and
11 things like that.

12 Q. I want to come on then before we break for lunch to
13 1983 and your involvement and the Society's
14 involvement in the developing AIDS crisis. I am going
15 to start in January 1983 and then we might look back
16 beyond that, but we will start in January 1983.

17 Soumik, could we have DHSC0002223_085. You will see,
18 Mr Watters, and you can ignore the handwriting at the
19 top, but you will see this is an Observer article from
20 Sunday, 16 January 1983 "Mystery disease threat", and
21 it's authored by Christine Doyle in Washington and
22 then it says, I won't go through all of it, but:

23 "A commercial blood product imported into
24 Britain from the [US] may pose a grave threat to
25 health of haemophiliacs who inject it to encourage

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1 Reverend Tanner to have known about an association
2 between AIDS and haemophiliacs before this article was
3 published?

4 A. Memories and dates with the passing of the years are
5 naturally a little hazy and I would need to look at
6 a chronology of events, really, and what the World
7 Federation of Haemophilia was saying and what the
8 National Haemophilia Foundation of the United States
9 was saying, but my guess is that we knew things about
10 the link between blood products and HIV at that time.

11 Q. Your observations are fair, Mr Watters. I won't
12 produce yet further documents but we know from July of
13 1982 reports emerging from the States of haemophiliacs
14 believed to be suffering from AIDS and we know that in
15 September of 1982 at the UKHDO meeting it was raised
16 as something that needed to be looked into further, by
17 Dr Craske. So it had been, as it were, something
18 flagged up over the preceding six months.

19 Is it fair to say the Society you'd expect
20 would have been aware of that?

21 A. We would have been aware of that. Although, of
22 course, we wouldn't have seen the minutes of UKHDO
23 necessarily, but word gets around.

24 Q. I will have to check the minutes but presumably
25 someone from the Society would normally have been

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1 there.

2 A. Yes.

3 Q. Was it, as far as you can recall, Reverend Tanner's

4 decision only to ask Professor Bloom and not the

5 Medical Advisory Panel more widely about this article

6 or was that your decision?

7 A. That would have been Father Tanner's decision, leaving

8 it to Professor Bloom if he wished to do so to consult

9 others on the UKHCDO.

10 Q. Then I think we've got a reply from Professor Bloom

11 for which I have, unfortunately, got two references,

12 and I'm not sure which is correct, Soumik. Let's try

13 both of them.

14 HCDO0000003_066. We have here

15 Professor Bloom's response dated 20 January 1983:

16 "Dear Mr Watters,

17 "Thank you very much for your letter ... and

18 for the cutting ... This cutting does seem to have

19 caused some concern amongst patients and indeed some

20 medical administrators and physicians.

21 "There may be a modicum of justification for

22 this concern. You are no doubt aware of the

23 background that a rather serious 'new' disease began

24 to be recognised towards the end of the 1981,

25 particularly amongst homosexuals in the USA."

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1 on the look out for this. As the full-blown condition

2 has not yet been reported amongst British

3 haemophiliacs it is not possible to state if the

4 coagulation concentrations produced in this country

5 are safer in this respect than the concentrates

6 produced in the USA. Indeed there is no evidence yet

7 in fact to implicate the latter."

8 Then he talks about investigations of possible

9 markers by directors of several centres:

10 "In the meanwhile there is certainly no need

11 for the haemophilic community to be unduly concerned

12 about this 'new' syndrome. They can rest assured that

13 every effort is being made to monitor the situation in

14 this country and to collaborate with the Centre for

15 Disease Control ..."

16 Then he talks about the position in relation to

17 haemophilia B.

18 Then he says:

19 "As you and your colleagues in the Society

20 know, coagulation factor therapy is so essential for

21 the safety and well being of patients that there is no

22 doubt whatsoever that their advantages far outweigh

23 this disadvantage which at the moment seems to be

24 potential rather than real in the UK at any rate.

25 Further developments will depend upon identifying the

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1 Then a few lines further down he says:

2 "However, later, as detailed in The Observer

3 article, several groups of people who are clearly not

4 homosexuals including various immigrant groups in the

5 USA as well as the ten haemophiliacs, were identified

6 as suffering from the disease. Clearly at the present

7 time the cause is quite unknown and neither has it

8 been proven that it's transmitted through contaminated

9 blood products. The incidence of the condition in

10 America is not known but seems to be about one per

11 thousand of the severely affected treated patients.

12 On this basis if the disease exists in the UK, we

13 could reasonably expect two or three cases amongst

14 British haemophiliacs. So far none have been

15 reported."

16 Then he goes on to say in the next paragraph

17 that the situation's being monitored by UKHCDO.

18 "At the meeting of our Hepatitis Working Party

19 this week, the meeting referred to in The Observer, it

20 was decided to institute a retrospective survey to all

21 Haemophilia Centre Directors and also a prospective

22 survey in order to try to detect any possible

23 emergence of this syndrome in the country. We do not

24 know at the moment if the condition exists in lesser

25 degrees of severity but we shall clearly have to keep

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1 responsible agent or constituent of concentrates, if

2 it exists, and no doubt then steps can be taken to

3 attempt to eliminate them in much the same way as

4 steps are being taken to reduce the risk of

5 hepatitis."

6 Then there is a reference to the possibility of

7 an article from Dr Craske.

8 Do you recall what the Society's response was

9 or reaction was on receiving this letter from

10 Professor Bloom? Was it reassuring?

11 A. I think at the time, based on what we knew, it was

12 fairly reassuring, but it wasn't long after this --

13 stop me if I'm going ahead of you, right -- that --

14 I remember we were at a board meeting at the Kennedy

15 Hotel, by Euston Station, and Clive Knight and I had

16 great trouble persuading the trustees, the Executive

17 Committee of The Haemophilia Society, that this was in

18 fact going to become a live problem in the

19 United Kingdom. Things were being said like, "Oh, you

20 know, we don't have bath houses in the United Kingdom

21 like they have in the United States", and we were

22 saying, "No, but we are certainly using the same blood

23 product", you know. And it was quite difficult to

24 persuade even a board made up of people with

25 haemophilia that this was in fact going to be a real

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1 problem that had to be faced and, of course, with the
2 benefit of hindsight, we know that we were possibly in
3 this letter of Arthur Bloom of 20 January not being
4 told the whole truth.

5 **Q.** One of the reasons why, as I understand it, you say
6 that, with the benefit of hindsight, you don't think
7 you were being told the real truth is you have
8 a recollection, Mr Watters, of a BBC journalist
9 showing you a letter?

10 **A.** Indeed.

11 **Q.** We can take this down, Soumik.

12 Can you just tell us what your recollection is
13 of that.

14 **A.** It was in May 2017, long after I retired and was
15 living here in Cornwall permanently, that the Panorama
16 programme contacted to come and film. After the
17 filming was finished they showed me a very heavily
18 redacted letter that came from a branch of the
19 Department of Health, possibly Public Health England
20 as it's now called, in which Professor Bloom was told
21 in no uncertain terms that he -- that there was going
22 to be a problem with imported concentrates but he at
23 all costs should make sure that the advice was always
24 given to patients that they should continue to take
25 their blood products as, as Professor Bloom said in

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1 shows that there was a meeting of Haemophilia Centre
2 Directors and some other clinicians, together with
3 Immuno, in January of 1983 at a London airport hotel
4 at which there was an update given of the current
5 knowledge about AIDS, cases reported in a transfused
6 baby in California and various other matters
7 discussed.

8 Can you recall whether that came to the
9 Society's attention at the time? Did you know
10 anything of that?

11 **A.** No, no. No.

12 **Q.** If we then look at, before we break for the morning,
13 HSOC0029476_022, please. We can see these are the
14 minutes of a meeting of the Executive Committee of The
15 Haemophilia Society on 3 March 1983. So we're now
16 a month and a half or so on from your exchange of
17 correspondence with Professor Bloom and The Observer
18 article and, in a sense, there's nothing in particular
19 to show you in this, Mr Watters. There's an absence
20 of any reference in this document to any discussion
21 about AIDS. Does it surprise you that by March 1983
22 the Society's Executive Committee was not discussing
23 the risk of AIDS in its committee meeting?

24 **A.** It does, it does. I cannot remember the meeting at
25 which Clive Knight and I intervened, as I described

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1 that letter we've just seen, the risks far -- the
2 benefits far outweighed the risks because this was
3 going to be a small problem.

4 **Q.** You weren't, I think, given a copy of the letter by
5 the BBC journalists?

6 **A.** I was shown it. I wish I'd had the presence of mind
7 to take it to the next room and photocopy it but
8 I didn't, and the people on the programme took it away
9 with them. And I think we've actually narrowed down
10 the people involved in preparing that programme and
11 hopefully that letter should still be in the file of
12 background research for the programme.

13 **Q.** Yes.

14 And I should say, sir, the Inquiry has taken
15 steps to see if we can obtain this material.

16 Do you have any recollection of what year the
17 letter was?

18 **A.** It was pre-1980, I think.

19 **Q.** Pre-1980?

20 **A.** Roundabout 1980, yes.

21 **Q.** No doubt if we manage to obtain a copy of it,
22 Mr Watters, we may ask you further in relation to
23 that.

24 Just sticking with early 1983, the Inquiry has
25 heard evidence from others and seen a document which

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1 a few moments ago, but I would have thought it was
2 around this time.

3 **Q.** And your recollection is that that was at a meeting at
4 the Kennedy Hotel? I think there were quite a few
5 meetings held at the Kennedy Hotel, so I don't know
6 whether that will assist us.

7 **A.** There were, there were.

8 **Q.** Did the Society ever get sent copies of the reports
9 that were published in the States in a publication
10 called the MMWR, which reported developments from the
11 CDC in Atlanta of new cases? Is that something the
12 Society received at this time?

13 **A.** We didn't receive them regularly. We would
14 occasionally receive them when the people in the NHS
15 office in New York remembered that the United Kingdom
16 wasn't in the United States and addressed it properly.
17 But about nine-tenths of the mail never arrived due to
18 wrong addressing.

19 **Q.** Do you recall the Society becoming aware and any
20 discussions taking place about the case of the baby
21 that was reported in December '82 and certainly came
22 to the attention of Professor Bloom and others who had
23 been transfused in the States and developed AIDS?

24 **A.** I have no recall of that.

25 **MS RICHARDS:** Sir, I note the time and the next series of

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1 questions I have for Mr Watters won't be completed
2 within five minutes; so I wonder if we pick those up
3 tomorrow morning.
4 **SIR BRIAN LANGSTAFF:** Yes, and tomorrow morning is right
5 because we have the lunch break and we come back after
6 lunch, do we not, to complete your presentation but
7 this is where Mr Watters leaves us for the day.

8 So thank you so far. What I said to you
9 earlier about not speaking to anyone about the
10 evidence, that continues over every break; so you
11 won't do that. But I look forward to seeing you back
12 here, same place, same time tomorrow at 10.00.

13 **A.** Thank you, sir. Thank you.

14 **SIR BRIAN LANGSTAFF:** For those watching remotely, be
15 aware that we will be continuing with Ms Richards'
16 presentation to me which did not conclude last week
17 and that will go on at 2 o'clock.

18 **MS RICHARDS:** Sir, in fact, I think it was 2.15 was the
19 time we published, so we probably should stick to
20 that.

21 **SIR BRIAN LANGSTAFF:** 2.15 in that case. That's the time.

22 **MS RICHARDS:** Thank you, sir.

23 (12.58 pm)

(Luncheon Adjournment)

24 (2.15 pm)

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1 matter -- and it involves looking at a document. It's
2 CGRA0000835, please, Soumik. These are extracts from
3 a newspaper in 2001. If we could go to page 5,
4 please, and we pick it up the bottom right-hand
5 corner, there's a picture there of Dr Jones and
6 a picture of Dr David Owen and then it says:

7 "Fears grew in 1960s."

8 So it's the very bottom right-hand corner:

9 "Doctors were warned of the risk of using
10 imported blood as early as the 1960s, a leading ..."

11 And then if we go to the next page, and if we
12 zoom in, it's on the right-hand, there's a line that's
13 missing on this photocopy and it reads:

14 "... a leading Newcastle scientist said last
15 night. Dr Arthur Codd, a consultant virologist ..."

16 This is all the bit that's missing -- sorry,
17 it's not that, it's the right-hand side, please.

18 Thank you.

19 So the bit that's missing is:

20 "... a leading Newcastle scientist said last
21 night. Dr Arthur Codd ..."

22 And you will recall, sir, his name coming up
23 when we looked at testing:

24 "... a consultant in the public health
25 laboratory service at Newcastle General Hospital ..."

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Presentation by MS RICHARDS, continued

2 **MS RICHARDS:** Good afternoon, sir. When we finished last
3 week the topics I had just been looking at were the
4 introduction of heat-treated products, numbers
5 infected with HIV at the Newcastle centre, and
6 Dr Jones' actions in raising concerns about the
7 possible transmission of AIDS by heat-treated
8 products.

9 Before I turn to the next topic, there are just
10 two further points to make in relation to those
11 matters. The first is in terms of the introduction of
12 heat-treated products to Newcastle, the Inquiry's been
13 shown over the last few days, very helpfully by Core
14 Participants, some records to suggest that
15 heat-treated products were made available to some
16 patients at the Newcastle centre in the course of
17 December 1984. So there are treatment records, for
18 example, that show heat treatment starting 7 and
19 14 December 1984. I mention that in particular in the
20 context of having looked at documents suggesting that
21 other patients were being asked or expected to use up
22 unheated products during that time or in early
23 January.

24 The second document goes back to issues about
25 knowledge of risk and hepatitis -- sorry, the second

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1 And then we pick up the top line on the
2 right-hand side:

3 "... said he and others had warned about the
4 risk of infection for many years.

5 "'We had known that pooling blood from many
6 donors increased risk of contamination as early as the
7 Second World War,' he said.

8 "'Hepatitis B was transmitted to many people
9 during this time and there was nothing we could do to
10 prevent it.

11 "'Crazy as it seems, a blood transfusion can
12 seriously damage your health and our recommendations
13 to only use blood from local donors were very clear.'

14 "'Until the UK started to import blood products
15 from America, it had one of the lowest rates of
16 hepatitis.

17 "'Now, the North-East has the highest death rate
18 among haemophiliacs in Europe.

19 "'No-one imagined there could be anything as
20 dreadful as HIV or Hepatitis C in the blood,' Dr Codd
21 said.

22 "'But we knew viruses were transmitted in this
23 way and we knew there was always a risk there might be
24 other things lurking there.

25 "'It was always my advice that we create

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a "pedigree herd" of volunteer donors in the UK in order to minimise the risk of infection.

"Dr Jones and other transfusion doctors were always considered to be ahead of their time by importing Hemofil. We could not have met demand at that time but we could have continued with the older products until Britain became self-sufficient."

"Dr Codd says it was well known the American pharmaceutical companies 'scoured the world for cheap plasma'."

Then he suggests that by the time we knew about AIDS the horse had bolted and it was too late.

Sir, I flag that up in part because it's very helpfully been drawn to my attention by a Core Participant to the Inquiry, but also because it shows what was being said, in 2001 at least, by the late Dr Arthur Codd, who was a consultant virologist in the 1970s and 1980s at the Newcastle General Hospital and who we have seen involved in some of the testing in the course of the 1980s. We can take that down, thank you.

The next topic is that of communication with provision of information to patients and treatment of patients. Sir, I'm not intending to go to individual witness statements from infected individuals or their

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Again, some statements from individual patients or their family members give a different account and the themes which emerge from the statements from Newcastle patients are very similar to the themes which emerge from the statements of patients at other centres.

It is right to say that there are some statements also which make positive comments about the quality of care and treatment received at Newcastle.

In terms of specific information provided to patients about the risks of hepatitis, if we look at Dr Jones' witness statement at WITN0841038, please, if we turn to page 54, please, we will see there's a series of paragraphs a., b., c., and on the next page d., in which what is set out are various written documents authored by Dr Jones at different times and we'll see in relation to the first, which was the spring 1976 newsletter from The Haemophilia Society -- we looked at it last week I'm not going to go back to it -- but you'll see there extracted into the statement his assertion in his newsletter article that "plasma from paid sources in America is now said to be almost as 'safe' as that from voluntary sources". The question that was asked of Dr Jones is "Did [that] reflect the information you provided to your patients at the time?" His answer is:

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families. We have referred to some individual examples in the written note but Newcastle was a large centre and there are a lot of statements to consider.

Whereas Dr Jones in his statements to the Inquiry has said repeatedly that all available information was shared with patients about risks, a different account is given in most of the statements that the Inquiry has received. Just picking up on some of the themes that emerge from the statements the Inquiry has received, they are a lack of communication about the risks of treatment; some instances of being led to believe or understand that factor products were safe and were a miracle treatment; examples of patients not being told of or asked for consent to testing, and only finding out tests had been undertaken when they were given the results; delays in being told the results of tests, diagnostic or indicative of viral infections, or not being informed of the diagnosis at all; a lack of care at the point of being informed of the diagnosis; and a lack of adequate information and advice following diagnosis.

In terms of how patients were told of their diagnosis following testing, we have Dr Jones' account, both to the Lindsay Tribunal and in his witness statements and I referred to those last week.

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"Yes."

And he says:

At the time ..."

So this is 1976.

"... the incidence of non-A, non-B hepatitis in multi-transfused patients was thought to be the same."

For both commercial and NHS.

Paragraph b. refers to a statement in one of Dr Jones' publications, *A Handbook for Home Therapy*, which talks about there being "always a risk of hepatitis virus being present in blood products and any of the materials you use could be contaminated".

He says that reflected the information provided to patients at the time.

Paragraph c. refers to statements made by Dr Jones in his book *Haemophilia Home Therapy*, in which he says:

"Every family knows that the use of human blood products carries the risk of hepatitis. They are aware that this risk has been linked particularly to commercial concentrates prepared from the blood of paid donors ..."

Which seems to be inconsistent with paragraph a. but, in any event, if we go over the page, in answer to the question "What steps did you

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take at the Newcastle Centre to make patients and their families aware of these risks?" he says:
 "Because we told them and they could read about the risk in patient leaflets enclosed with the concentrates and in literature from The Haemophilia Society."

Obviously, we have been discussing the latter this morning with Mr Watters. I'll come back to patient leaflets. Then he said there were regular meetings. Then at paragraph d. he's referred to what he said in the autumn 1980 newsletter, that:

"... although risks [of ... infection] remain they are probably of less consequence than might be suggested by the literature, and are certainly outweighed by the need to treat haemophiliacs bleeding in the only way we know."

He's asked the question: "Did this reflect the information which you provided to your patients at the time?"

That's not answered in terms. The answer is to the earlier question. Then he says:

"Our patients knew what we knew at the time."

Sir, it may be that in due course you will wish to consider whether looking at these various statements, if this was the information provided to

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the newsletter it will be there in that document.
 But, no, nothing else given in the statement.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: We can take that down, Soumik, thank you.

Dr Jones also has said in his statement -- we don't need to go to the statement for this -- that by the end of the 1970s he told his patients they were inevitably infected with non-A, non-B hepatitis.

Again, sir, there is patient evidence to the opposite effect and, no doubt, that's something you will wish to consider in due course.

In terms of the reference in the passage we just looked at to patients having information from product leaflets, and that's a point that Dr Jones makes in his statements, I think, on more than one occasion, three points to consider. The first is that such leaflets would not in any event be accessible to those treated in hospital, and those infrequently treated, who would simply have the treatment administered to them. They would only be accessible to those receiving home treatment.

Secondly, of course, it assumes that patients read and understood what was being said in the product leaflets or product inserts.

Thirdly, of course, it depends upon what those

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patients and obviously some patients at least say it was not, you may wish to consider whether that would have given patients a clear understanding of the risks or whether they might have been left in a state of some confusion.

SIR BRIAN LANGSTAFF: Can we just go back to a. on the previous page.

MS RICHARDS: The page before that.

SIR BRIAN LANGSTAFF: Little a., if you can just highlight that, please, Soumik, he's asked:

"What was your basis for the reassurance that commercial plasma was almost as safe as plasma from voluntary resources?"

You pointed out that's inconsistent with what is said below at c. but what he says is:

"At the time the incidence of non-A, non-B hepatitis in multi-transfused patients was thought to be the same."

Thought by whom? Does he ever give any source for that?

MS RICHARDS: No. No, there's no source in the statement and we looked at the newsletter last week I can't recall there being any source in the newsletter. You will recall that was the newsletter responding to the World in Action documentary. If there was a source in

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leaflets or inserts actually said and we will, sir, in due course at a later hearing, probably when we look at pharmaceutical companies in more detail, we will look at what is said in the various different product leaflets over the years about the risks of hepatitis.

SIR BRIAN LANGSTAFF: I think since about 1972, at least one of the companies was putting a warning as to hepatitis without differentiating between B, non-A, non-B hepatitis, et cetera, but it was warning about hepatitis as a consequence of using this product, as a risk.

MS RICHARDS: Yes, and of course --

SIR BRIAN LANGSTAFF: So it was clearly early on in the 1970s that at least one company, and then others followed suit in the later 1970s, warning about the risk of hepatitis.

MS RICHARDS: Yes, and of course one question that you may wish to consider in due course, sir, is whether what is said in a product leaflet, a product insert, is in any form a substitution for the giving of advice about risks by a clinician to a patient.

In relation to HIV and AIDS, Dr Jones' position in his statement -- or his statement that patients were told everything that they knew. Again, you will no doubt wish to consider that as against the evidence

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from individual patients and their medical records. Reference is made by Dr Jones in his statement, and I think has been made by other clinicians in their statements, to a book published by Dr Jones called *AIDS and The Blood* -- sorry, a book written by Dr Jones, I should say. Soumik, it's RLIT0000046.

We see there it's *AIDS and The Blood, a Practical Guide* by Dr Peter Jones. If we go over the page we can see the date towards the bottom. So it's first published February 1985. So it is more concerned, as it were, with the extent of infection in haemophiliacs having begun to be understood. This is the provision of information at that stage, rather than the provision of advice or warnings about risks in advance of treatment.

Then there are just two paragraphs in the book itself I'm going to refer you to for present purposes. Could we go to page 7, please, Soumik. Sorry, it will be two pages further on, electronic page 9. Just picking up towards the bottom of the page, last sentence before the table:

"... this syndrome is rare, and present evidence is that the great majority of people exposed to the HTLV virus are not harmed by it."

So that's the information being given to

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SIR BRIAN LANGSTAFF: So he is reassuring there as to the number of people who, at the time of writing, as he sees it, were harmed, whereas in the previous paragraph he's dealing with those who will eventually develop it.

MS RICHARDS: Yes, that may be right.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: Then if we go to page 25 of the book, which I think is probably page 27 electronically, Soumik, we see this is the message from Dr Jones in the book:

"Should I stop my haemophilia treatment?"

"No.

"Bleeding causes more crippling and premature death in haemophilia than AIDS has or is ever likely to do."

Then he says in the next paragraph:

"When the AIDS scare started doctors caring for haemophiliac families reassessed all forms of treatment available to them."

Pausing there, sir, you will obviously wish to consider whether that correctly reflects the evidence that you have read and heard:

"For a while there was a cut back in the use of concentrates."

Again, sir, you will wish to consider whether

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patients as at early 1985 in this book. Then if we go on to page --

SIR BRIAN LANGSTAFF: Just let me read it through and let those at home read this through as to what was being said.

(Pause)

The second paragraph there, the second sentence:

"Estimates about how many will eventually develop AIDS vary widely."

So there he's looking at the risk that those who have HIV or HTLV-III will eventually develop AIDS. He plainly is recognising that, at least in the views of some, AIDS is a long-term consequence of HTLV infection. What's he looking at in the last paragraph?

MS RICHARDS: There he's looking at how many, who have been exposed to the HTLV virus, will develop AIDS, I think.

SIR BRIAN LANGSTAFF: It's difficult to know because he's not actually looking at long-term rates from infection. Current evidence is that they are not harmed by it, as opposed to will be harmed by it. It's a different issue.

MS RICHARDS: You may have been right, sir.

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you have seen evidence to support that:

"Naturally, some people with haemophilia were reluctant to treat themselves with what they saw as a potentially dangerous blood product. Companies in the [US] reported a 20 per cent fall in blood product consumption.

"Once the dust settled fact began to impress itself again, and fact is that haemophilic bleeding has to be treated. However, modifications might be made both to blood products and how they are used. These are described elsewhere."

Then he goes on to talk about -- well, perhaps for the sake of completeness, we should go over the page. So the question is posed "Should I modify my haemophilia treatment?" He says:

"You should certainly examine your treatment needs, or those of your child."

There is then -- the first indented paragraph talks about whether to use -- how much factor concentrate is being used, and then there are various other suggestions:

"- are you sure you are treating bleeds? ... If you are not absolutely sure think about disobeying the rule 'if in doubt treat' for a while."

Then there's a discussion about prophylaxis and

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about whether you're overdoing things and then the last is about perhaps deferring surgery.

Sir, these are all suggestions being made in this book. Again, you may wish to consider the extent to which those are options that were, as a matter of fact, or should have been implemented in centres earlier.

Then there is a later discussion about heat-treated products but I don't propose to take you to those.

That's some extracts from Dr Jones' book *AIDS and The Blood*.

In terms of the arrangements that were made for the treatment of patients diagnosed with HIV, we've set out in our written note some of the staffing provision that there was at the Newcastle centre, including the availability of social workers. There is evidence to suggest that in or around 1987, Dr Jones and a consultant in infectious diseases, Dr Mike Snow, at Newcastle, established some form of liaison or joint care and that's set out in Dr Jones' statement and also referred to in Dr Hamilton's statement. It is clear, however, that Dr Jones continued to be involved with the care of patients not just for their haemophilia but in respect of HIV and

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telling patients the result of their hepatitis C testing, as opposed to what he said was the system for HIV testing, and that patients would be eventually told their diagnosis at the next follow up they attended, which could be some time into the distance. Of course, there is, I should say again, evidence from individual patients to show that hepatitis C testing at the Newcastle centre might have taken place over quite a prolonged period of time.

There is some evidence of early testing for some patients in 1989. Others have not been tested until 1994. There's evidence of infrequently treated mild haemophiliacs, as with other centres, not being tested early or not being informed of their diagnosis properly because of a lack of follow up. So, again, similar things from the themes we have seen in relation to a number of other centres.

I turn next to the question of death certification. We've set out in our note evidence of a decision having been made by the coroner local to the Newcastle area that there would not be a need to hold an open inquest on all AIDS-related deaths, and it appears the motivation there was to preserve the anonymity of the families.

In terms of the practice of Dr Hamilton and

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AIDS, although he records in his statement some individuals requesting their follow-up to be simply with Dr Snow.

Sister Fearn's in her statement recalls Dr Jones, for example, leading an AZT trial.

In terms of the treatment of those who were later diagnosed as suffering from hepatitis C, Dr Hamilton's statement records the running of a weekly clinic for haemophiliacs with HIV and with hepatitis C, and he refers in 2000, so upon Dr Jones' retirement, not long before his own, to a joint clinic being established with a newly appointed infectious diseases consultant.

Sir, I touched last week on the issue of testing for hepatitis C. There is little documentary evidence, contemporaneous documentary evidence, other than that which emerges from individual patients' medical records and is referred to in their witness statements. The closest we have to any kind of narrative account of the process for testing for hepatitis C is Dr Jones' evidence to the Lindsay Tribunal which we looked at last week and so I won't go back to, but you will recall him acknowledging before the Lindsay Tribunal that there was a difference in terms of urgency, in terms of

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Dr Jones, they talk in UKHCDO meetings in the early 1990s of there being a good relationship with the coroner in the Newcastle area. Dr Hamilton is quoted as saying "I didn't put HIV on the death certificate but made sure that the coroner knew about it". If we just go to what Dr Jones said on the topic in a UKHCDO meeting it's HCDO0000493. We can see it's a meeting of 1 October 1993 and, if we go to page 6, please, the top paragraph, this is in the context of a discussion about HIV statistics, halfway down that paragraph, so about six or seven lines down, it says:

"Dr Jones said that he did not put AIDS, etc on the death certificate. There was some discussion about this and about the way that Directors filled in death certificates. Dr Jones was concerned that the information used when analysing the deaths of people with haemophilia should be the information provided by [doctors] and not just the information, as given, on the death certificate."

Then:

"He was reassured that it was the Director's information that was used when compiling the Annual Returns and other reports."

But we can see there, in any event as a matter of fact, Dr Jones, like Dr Hamilton saying that AIDS

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would not be put on the death certificate.

In terms of medical records, Dr Jones' statement suggests there were medical records kept in the centre itself in the Victoria Royal Infirmary, separate to the hospital records system. He also describes there being treatment record cards -- I can't recall whether it's Dr Jones or a document that refers to these as green cards -- in addition to the medical records, and these record cards or green cards set out the patient's personal information and noted information about each treatment, and they too were kept separately to the medical records.

Sister Fearn in her statement recalls those being removed from the centre in the late 1990s for scanning and her understanding that they were thereafter stored electronically.

Still on the question of data and records in the context of the information provided to Oxford as part of the Oxford returns, Dr Jones in his witness statement has said that all his patients knew that anonymised data was shared principally in relation to the Oxford returns but that specific consent was not thought to be necessary. Again, that specific consent was not thought to be necessary seems to be the view of a number of other directors at the time.

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I want to look at for present purposes. In it, and the date is 14 October 1986, Dr Jones sets out to The Haemophilia Society his view that it's wrong that highly personal details about HIV status and AIDS should be divulged without individual informed consent, and he expresses concern about whether that is The Haemophilia Society's position or not. As I say, I'll take up the Society's position with Mr Watters in the course of the week but you will see there what Dr Jones was identifying as his particular concern.

Sir, there's then the issue of vCJD. I'm not going to go into this in much detail because, for the most part, the notification process was, as it were, a centrally organised one with which most Haemophilia Centre Directors complied but it may be instructive to see what Dr Hamilton, who was the consultant largely concerned with this, has to say in his statement.

Soumik, it's WITN4197005.

If we go to page 36, please, we can see under the heading "vCJD", Dr Hamilton setting out how the matter was approached in the Newcastle centre. He says he would have been made aware of vCJD potential contamination in 1997 when Sister Fearn discussed the problem with him, and then he recalls the advice from

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Of course, the Inquiry's seen evidence to show that it's not just anonymised data that was shared with the Oxford Haemophilia Centre but data setting out patient names and patient details.

There is a reference in one of the contemporaneous documents to Dr Jones not returning to Oxford details of patients with HIV infection. Dr Jones, however, in his statement said that's actually incorrect and that he did supply data to Oxford, including about patients with HIV infection but not information in relation to sexual partners.

It's also right to note that in UKHCDO meetings in the 1980s, in July 1986, Dr Jones had raised concerns about data handling in Oxford. He raised, at a meeting on 2 July, a view that patients should be asked to give informed consent to data being entered into the Oxford system and he felt that patients had a right to know that their names and personal details were being so held. The outcome of that particular meeting was to obtain legal advice.

Then if we go to HSOC0015334. This is a set of documents that I will no doubt be asking Mr Watters about in the course of this week, but if we go to the third page we'll see what triggered Mr Watters' memo, and it's a letter from Dr Jones and it's just that

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the Lothian Ethical Committee, that patients should not be informed that the product had been recalled for vCJD reasons and says this:

"Both Sister Fearn and myself were very unhappy about this advice because it was our policy to be honest and open with our patients. I wrote to several people expressing my concerns. I am afraid I do not now remember why the Lothian Health Board were involved at that time."

Then he goes on in the next paragraph to say:

"In the centre, against our better judgment, we followed the advice issued which was to be economical with the truth in telling the patients why the product was being recalled."

From which I infer it was to follow the advice of the Lothian Ethical Committee and not tell patients the reason for the recall.

He then, in response to the question of how and when were patients told of possible exposure to vCJD, he refers to the issue arising in around January 2001 and a letter that he wrote to all patients explaining the situation.

If we can look at that, it's NTH0000006_002 and we can see it's dated 22 January 2001. It's, I think, a round robin to patients:

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"You may have received a letter from The Haemophilia Society ..."

It refers to the information that the Haemophilia Centre Directors have received.

Fourth paragraph:

"... no reports of any cases of vCJD in haemophiliacs or in other patients receiving blood transfusions or blood products."

And then over the page we can see the approach that was taken. So he says:

"As we have been provided with the batch numbers of these products, individual patients who have received treatment with these have been identified."

"This letter is being sent to all patients, irrespective of whether they have received the currently implicated batches, so that you are aware of this occurrence and as there is the possibility of further notifications in the future."

"Some may wish to know whether they/their child have received one of these batches, while others may choose not to know this information at this time as the risk is theoretical and there is no test available at the moment to confirm if vCJD can be transmitted in these circumstances. You are asked to think which

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establishment of a trial of prophylaxis therapy in both Treloars and Newcastle. Dr Jones is unable to recall involvement in that now.

Thirdly, there's a study with Treloars on the claim that high potency Factor VIII had a longer *in vivo* half-life than other materials. Again, Dr Jones has been unable to recall any involvement in that.

Then in 1984 there's an investigation of the incidence of hepatitis in haemophiliacs, particularly those with mild or moderate haemophilia, following an infusion of Koate, and the documents suggest that Dr Jones was to be the or a trial co-ordinator in relation to that.

In particular in relation to the involvement of Treloars or the undertaking of research in co-ordination with Treloars, we will be looking at that later, in later hearings, when we look in more detail at the position of Treloars and set out what research we understand to have been undertaken there, so we may well come back to that issue and to Dr Jones' involvement in that regard at a later stage.

We touched this morning with Mr Watters on the Medical Advisory Panel, and Dr Jones was heavily involved with The Haemophilia Society over a number of

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approach you would prefer to adopt.

"For patients who have received any of these batches, the information will be recorded in their hospital notes in case it may be important for their care in the future."

Then he talks about the risk from beef. Then the last paragraph, an offer to ring Sister Fearn or have an appointment with Dr Hamilton. So we can see from that the choice being given to the patient as to whether to be informed if they received one of the identified batches.

Sir, the next topic is in relation to research. We've set out in the note information available to the Inquiry about research in which Dr Jones was involved.

Dr Jones' statement essentially contains the response that he has no recollection now about these matters. I'll just identify briefly four of the areas of research that have been identified which he doesn't recall.

There's reference in the documents, first of all, in 1976 to involvement in a study of the incidence of hepatitis in haemophilia patients in collaboration with Treloars. Dr Jones doesn't recall involvement in that now.

There's then reference in 1980 to the

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years, including through sitting on the Medical Advisory Panel. There is a reference in The Haemophilia Society materials to Dr Jones having made a special plea for inclusion when the Medical Advisory Panel was being restructured in the early 1990s, and a report from Mr Watters at the time suggests that the Society was retaining him as he was seen as a youthful and skilled communicator and an experienced paediatrician.

There's one document which appears to record a discussion between Dr Jones and Mr Watters about compensation which it may be worth looking at, and which we may want to ask Mr Watters about in the course of the week.

Soumik, it's PJON0000134_001. We'll see it reads:

"Meeting with David Watters 13.6.89."

It's not obvious from the document that it's a meeting with Dr Jones but it is a document that's been provided to us by Dr Jones, amongst Dr Jones' own papers, and so -- and we know also that Dr Jones was involved with The Haemophilia Society's campaign for compensation in the latter part of the 80s.

So the assumption that we've made is that this is a note of a conversation between or a meeting

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1 between Mr Watters and Dr Jones.

2 I'm going to read it out because it's an
3 interesting document in its own right but no doubt
4 Mr Watters maybe able to assist us in due course this
5 week as to whether this records a meeting that he had
6 with Dr Jones or someone else.

7 So it says this:

8 "Everything points to some central government
9 secret, possibly in the late 1970s/early 1980s,
10 involving members of the Cabinet. The solicitors
11 acting on behalf of the haemophiliacs are going for
12 disclosure of government records assumed to be within
13 the Committee on Safety of Medicines, in the hope that
14 they will embarrass government to give an out of court
15 settlement. This may be along the lines of the
16 Vaccination Damage Bill which would only result in
17 between £20,000-40,000/head. Remarks made by David
18 suggest that present members of the Cabinet are
19 vulnerable and because of this I suspect that the
20 information will not lie within the Committee on
21 Safety of Medicines. A civil servant working for
22 Norman Fowler has let it be known to David that it is
23 considered within the department that government is
24 vulnerable and that an out of court settlement should
25 be made. A similar message was given to us at the

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1 would also explain why the publicity at the beginning
2 of the AIDS epidemic in Britain was deliberately
3 shifted, on higher authority, from Glasgow to
4 Newcastle."

5 That, again, supports the inference that this
6 is a document produced by Dr Jones but I'm afraid we
7 only received this after his statement had been
8 received so we haven't had an opportunity to ask him.

9 "Peter Bottomley has made initial moves towards
10 David Watters with regard to further financial help
11 for haemophiliacs ... but David things more probably
12 initial feelers from central government prior to being
13 vulnerable in the run up to the next election. The
14 planned Haemophilia Society campaign, which will use
15 Newcastle in the same way as the last campaign, will
16 probably start in the Autumn and will be directed at
17 the Front Bench, and not to run as a public campaign.
18 On no account must it be made a party political issue.

19 "As far as colleagues are concerned they should
20 be aware that The Haemophilia Society wishes to help
21 affected families achieve a financial settlement which
22 makes them individually responsible for their own
23 financial affairs. I.e. not having to go to charity
24 for every grant, which the Society feels is putting
25 off a lot of people from seeking help in the first

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1 meeting at the Ministry by Tony Newton, who was at
2 pains to avoid any connection between contamination of
3 blood supplies and decisions taken by him in the past.
4 We know that the decision for the £10 million pay out
5 was taken directly by Mrs Thatcher on the afternoon
6 that a question was raised in the House at the
7 beginning of the campaign. We suspect that the
8 Scottish Blood Transfusion Service was primed with
9 foreign plasma in order to become self-sufficient, and
10 there has been a recent reference to this which I must
11 find. If this is true then the scenario could be that
12 secretly government bought foreign plasma from plasma
13 brokers or possibly directly from industry, and that
14 there may be a link here to the development of AIDS
15 and third world countries. The reasoning could be
16 that it was cheaper to buy the raw product than the
17 finished product using the facility which was not
18 running to capacity. It would have had to be Scotland
19 because Elstree did not have the capability for
20 processing large amounts of plasma at this time."

21 **SIR BRIAN LANGSTAFF:** We are not on the same page. There
22 we are. Thank you.

23 **MS RICHARDS:** "This scenario would explain why Scotland
24 became self sufficient despite not appearing to have
25 enough donors, and is not longer self sufficient. It

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1 place. Their aim is exactly the same as the
2 solicitors, and that is to seek out of court
3 settlement from government which would not involve
4 doctors and individual centres. The Society are
5 acutely aware of problems which may arise with the
6 doctor/patient relationship, and are going to use this
7 in any future dealings with the Department of Health
8 as one of the points in their campaign."

9 So as I say, sir, I will ask Mr Watters about
10 that in the course of the week but it appears, at
11 first blush, to be possibly be a document setting out
12 the outcome of a meeting between Mr Watters and
13 Dr Jones and to include the latter's reflections.

14 It's right to note that Dr Jones in his witness
15 statement has provided more information about his
16 involvement with The Haemophilia Society and
17 campaigning for compensation. He's also set out in
18 his statement, and I'm not going to ask for this to go
19 on screen, I'll just read it, his view in relation to
20 the Macfarlane Trust. He says this:

21 "I remember being of the opinion at the time
22 that the available money should be divided up and
23 distributed immediately to those affected. My fellow
24 trustees disagreed with that view, arguing that
25 payment should depend on demonstrable individual needs

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1 and that is the principle on which the trust worked."

2 Dr Jones was a trustee of the Macfarlane Trust
3 in its early incarnation from 1988 to 1991, and that
4 is presumably the period he is referring to.

5 Sir, the penultimate topic is in relation to
6 Dr Jones' connections with pharmaceutical companies.
7 He appears to have had two particularly strong links
8 to pharmaceutical companies. In the mid-1970s,
9 1975/76, he was invited to consider applying for the
10 post of medical director of Baxter Travenol, based in
11 the States, and in his statement he says this:

12 "As part of the negotiations on whether to
13 accept this post, I visited their head office and
14 their fractionation plant at Glendale in Los Angeles
15 in 1976. Subsequently Travenol suggested that if
16 I did not wish to take the worldwide post based in
17 California I might be interested in becoming the
18 European medical director working from Brussels. Thus
19 it was that in 1977 the then Newcastle Area Health
20 Authority give me paid leave of absence once a week
21 over a three-month period to go to Brussels to assess
22 the job."

23 I think I said that was in his statement.
24 That's in his personal record document that I referred
25 to last week.

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1 such as 5 on the enclosed draft agenda are discussed."
2 Item 5 over the page on the agenda was "Supply
3 of Factor VIII and purchase of commercial
4 Factor VIII".

5 Dr Jones' response is at PJON0000051_001. He
6 says this in his letter of 19 November 1976 in the
7 second line:

8 "I understand exactly the position. Indeed,
9 this is why I have gone out of my way to make it known
10 to everybody concerned that I am at present acting as
11 a consultant to Hyland. I would, however, like to
12 make it absolutely clear that I am not concerned with
13 the sales of this organisation but purely with
14 a consultancy on medical matters."

15 Then, in the third paragraph, he says:

16 "I would be perfectly prepared to declare an
17 interest officially and if necessary withdraw from
18 meetings, but would obviously like to retain the right
19 to add our Newcastle figures and experience into the
20 melting pot, perhaps through the means of a written
21 report. I could always argue that not a little of
22 research and travel conducted by our colleagues is
23 sponsored by commercial firms. The job is anyway only
24 on a temporary basis for a trial period of six months
25 to see how a part-time consultancy will work out.

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1 There is a reference in contemporaneous
2 documents to other Haemophilia Centre Directors being
3 concerned about a possible conflict of interest.

4 If we go to PJON0000050_001, we can see here
5 that Dr Biggs wrote to Dr Jones in November 1976, in
6 advance of a Haemophilia Centre Directors meeting,
7 saying this in the third paragraph:

8 "Several Haemophilia Centre Directors have
9 mentioned to me a little about your position
10 representing the Newcastle Haemophilia Reference
11 Centre while you are working for Hyland.

12 "The situation is a delicate and difficult one
13 since everyone recognises the very major contributions
14 that you have made to Haemophilia treatment both in
15 the Newcastle Region and in the United Kingdom as
16 a whole. I think that we all feel that we could
17 certainly not do without your presence at the
18 Haemophilia Centre Directors Meetings both as
19 representing Newcastle and in your own capacity as an
20 expert. On the other hand topics such as the supply
21 of Factor VIII are rather confidential as are the
22 'discussions' that go on about the NHS supply of
23 Factor VIII. I wonder if you will like to consider
24 the Parliamentary procedure of 'Declaring an Interest'
25 and possibly withdrawing from the meeting when items

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1 I certainly do not want to go full time but nor at
2 present do I really want to lose financial and other
3 advantages which were becoming apparent. It may be
4 I will be thrown out at the end of February but I
5 would like to continue to have my cake and eat it if
6 possible."

7 Then -- sorry, I should just perhaps read the
8 next paragraph:

9 "Initially very antagonistic but curious,
10 I have been very impressed with the things I have seen
11 in the commercial company and really cannot understand
12 why we don't make more use of their expertise."

13 If we then go to PRSE0002268, we can see these
14 are minutes of the Haemophilia Centre Directors
15 meeting on 13 January 1977, which is the next meeting.

16 If we go to page 10, please, Soumik. It's the
17 page numbered 10. There are some extra pages in here,
18 so perhaps we go forward. Try going forward four
19 pages. That's it.

20 Halfway down the page, we can see there's
21 a heading "Activities of Reference Centre Directors
22 and the Supply of Factor VIII". Then if we look
23 towards the bottom of the page there's -- a Dr Holman
24 comments that:

25 "... Directors had for years said that they

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wanted concentrate instead of cryoprecipitate. Was it true that DHSS were making no provisions for expansion?"

Then Dr Jones declared his interest, as set out in the correspondence with Dr Biggs:

"Dr Jones declared his interest in this item as he was a paid Consultant to Hyland Laboratories until the end of February [top of the next page] 1977 and he volunteered to withdraw from the meeting while the question of supplies were being discussed. It was agreed that he could stay."

So, contrary to the concern that had been expressed, it appears that he stayed and participated in the meeting, although he declared his interest through his work.

The second involvement that we know Dr Jones had was in 1979 when he was employed as a consultant by Revlon Health Care group. He puts it this way in his draft personal record, if we go to WITN0841007, there's no underscore.

I should have said for the sake of completeness, he decided not to take the job that was referred to in the documents we've just been looking at. If we go to page 28, please, in the first main paragraph, he says this:

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Then you will see that there is a discussion about plasma supplies to Travenol being from and it's said "Betise and Lesoto", (sic) I think that might be Belize, and further discussions about Travenol. There's then a discussion about Immuno in the next paragraph and if we go over the page --

SIR BRIAN LANGSTAFF: Can you go back to that, just the middle paragraph, Immuno. So the Immuno are making two products, one made from plasma bought from the States and one said to be made in Europe which, in fact, contains plasma bought from the States. So Immuno were marketing, it would appear, a factor product which was more expensive because it was said to be made in Europe.

MS RICHARDS: That seems to be what is being said here in the course of this meeting, yes.

SIR BRIAN LANGSTAFF: So in 1979 they thought there was a trading advantage reflected in the price, in demonstrating that they were using lower-risk product.

MS RICHARDS: Yes.

SIR BRIAN LANGSTAFF: The implication might be that, as far as they were concerned, that they thought the risk of hepatitis was not simply so mild that it could be ignored and might not have a justified price differential.

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"I had further knowledge of the commercial blood industry when in 1980 I was employed as a consultant by the Revlon Health Care Group to give them an objective assessment of their plasma procuring centres which both then and now are run by an organisation called Plasma Alliance Inc, chiefly in the central United States with headquarters at Knoxville, Tennessee. The report to that company was confidential and I have no copy, but my general conclusion was that the Centres were extremely well run. The standard was certainly not in accord with the more usual public image of skid row donations in the densely populated conurbations of east and west seaboard of the United States."

We can see if we look at WITN0841028, an account by -- well, it's not clear if it's by Dr Jones. It may well be and, again, it's been provided to the Inquiry, I think, by Dr Jones but an account of dealings he had with Revlon in 1979. It's headed:

"Dr Peter Jones,
"Strictly confidential memorandum re: Paris trip 14-17 September, 1979.
"Meeting with Robert Taub and
Wolfgang Marguerre."

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MS RICHARDS: That may well be an inference, sir, that you would be entitled to draw.

SIR BRIAN LANGSTAFF: (*Unclear audio*) would it not?

MS RICHARDS: Yes.

SIR BRIAN LANGSTAFF: Yes, thank you.

MS RICHARDS: I should say also, in the previous paragraph which talks about Travenol, there's reference to what's said to be an intention that Travenol will gradually withdraw from the fractionation business and a reference to the cow having been milked dry.

If we go over the page then, the meeting turns, or the note turns, to the organisation of the Revlon Health Care group and it's said the headquarters of Armour are in Phoenix, Arizona. There's then a discussion about the company.

If we look towards the bottom of the page, we can see that the person recording this, which as I say it appears it may have been Peter Jones:

"On Monday, 17th September, 1979 in session with Marguerre and Taub the following points -- in addition to those already mentioned -- emerged."

Then there's reference to a new Hyland product. There's criticisms being expressed of the management of plasma sales from Armour with regard to the UK, and then if we go over the page it's said there are two

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objectives. One is to do what's called try and validate the Bonn approach and second to throw open the whole of plasma collection and marketing in the United States to independent scrutiny.

Then we can see it says:

"In order to achieve these two objectives and later hazily sketched ideas to develop a major commitment to funding national and international meetings, symposia and research and development in the clinical sector, it was proposed that PJ [so Dr Jones] became a 'consultant' with direct access to Marguerre and Taub and with authority to approach any physician or scientist he wished in order to set up programmes."

Then there's a discussion of the political situation in Germany:

"PJ agreed that he would be willing to participate in a scientific study of the new Factor VIII product being introduced by Armour in conjunction with Doctors in Bonn."

Then there's a further discussion about that. It's suggesting it might be a step toward achieving access to the Bonn Centre.

"It was stated that if PJ were acceptable to Bonn -- and the approach would be cautious and through Taub -- it was hoped that should the approach both

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that in order to back up claims for the new 'clean' Factor VIII product being launched by Armour, that efforts be directed into looking at possible long-term side effects of intensive transfusion therapy. In the first instance PJ suggested that extensive animal experiments be conducted by Armour, this suggestion being received with acclaim. It was, however, suggested that first evidence of morbidity would be likely to be in Bonn where the highest doses over a period of time had been used. It was realised that this was another way of approaching the Bonn problem."

Then there are some further points about the new product, and then "Conclusion":

"No finance is discussed, apart from statement of full financial support for studies conducted through PJ with complete expenses and reimbursement for personal time."

Then in capital letters and speech marks:

"WE INTEND TO UTILISE YOUR BRAIN."

There was indeed a visit by Dr Jones to facilities in the United States, and if we go to -- I can't find the report -- PJON0000040_001, please. We can see it's headed "Revlon Health Care Group, A Report on Plasmapheresis in the United States". Over the page it's reported as being confidential to

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with home therapy and antibodies be validated or invalidated by the data that PJ would help to present it as Bonn lacked anybody of sufficient calibre in this field."

Then it says:

"With regard to the second objective, it was suggested that within the coming weeks a gradual dialogue be established between PJ and Revlon Health Care and that this should culminate in a visit to the facilities in the United States. It was stated that PJ could invite anybody from the scientific field (Arthur Bloom in particular being mentioned) to accompany him on this trip, the purpose of which would be to validate the company claims of collection and fractionation independence. It was also mentioned that Revlon presently put 9% of their profit into research."

Over the page:

"PJ stated that he would go along with the project with the provisos that it was fully understood that there were no strings attached, that he remained in Newcastle, and that any commitment made by either the company or himself was known to his colleagues. This was agreed.

"He suggested that it was of primary importance

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Mr Marguerre, the Vice President, Biological Products, Revlon Health Care Group.

If we go to the next page, we can see the contents -- not going to go through the detail of it but just to outline what we have -- if we go over the page we see the introduction authored by Dr Jones:

"In 1979 Mr W Marguerre, on behalf of the Revlon Health Care Group, invited Dr Jones to visit Group facilities for the collection of blood products in the United States.

"Revlon's interest in the medical field had been strengthened by the acquisition of Armour International, and by the creation, in late 1978, of an organisation for the plasmapheresis of donors within the Group. It was Group policy to achieve self-sufficiency in source plasma, and to this end Armour Pharmaceuticals had acquired the company Plasma Alliance, operating in the [USA].

"Dr Jones' brief was to visit a number of plasmapheresis centres managed by Plasma Alliance, to talk with management, staff and donors and to report his findings to Mr Marguerre. It was an essential understanding within this agreement that 'there was nothing to hide', and that the open nature of the visit was designed to demonstrate that Plasma Alliance

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were a sound, healthy and ethical organisation. On his part, Dr Jones agreed to report back, in confidence, directly to Mr Marguerre.

It "is the purpose of this report to set out the results of the United States visit."

We can see it is dated by Dr Jones, June 1980. If we go to the next page we can see the programme of visits, so carried out in February and March, early March, 1980 to various centres.

If we go to page 11 -- sorry, Soumik, can we go on three pages. It's page 11 using the numbered pages.

There's a section of the report headed "Conclusions and Recommendations". I'm not going to go through it page by page, sir, but you will see it says "General -- The Centres":

"General standards were excellent, and there was nothing to criticise in the caring attitude shown by staff at all levels."

Then the report goes on to look at an individual centre, to set out various matters relating to emergency kits, donor health and others.

So that's the visit undertaken by Dr Jones in 1980 following his meeting in Paris and the report he then prepared. His report was used as the basis for

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health and welfare of staff working in the centres and, of course, the donors and included ..."

Then there are three matters set out. Then it's said:

"The recommendations made by Dr Jones have been implemented wherever possible in order to maintain the highest standards throughout the Plasma Alliance Group.

"The publication of Dr Jones' comments on what he saw follows his own recommendation, couched in the following terms:

"The "bad" image associated with procedures involving paid donors has not been helped in any way by secrecy. The organisation managed by Revlon Health Care and Plasma Alliance Inc is, in my opinion, of so high a standard that it lends itself to a more open attitude. I strongly recommend that consideration be given to more exposure (within the bounds of necessary industrial security)."

I should add that Dr Jones in this statement has said he was unaware that his confidential report would be used in promotional material.

In the written note, we've referred to a possible visit to a Hyland facility in Lasne in Belgium, suggesting that was a visit made and a report

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a publication called *Plasma Perspectives* in 1981.

And the reference for that, Soumik, is ARMO0000229.

This publication is called *Plasma Perspectives*. It's dated July 1981. If we go to page 8, please, the article at the top of the page says "Armour follow 'nothing to hide' policy", and it says this:

"To allay the emotive and unsubstantiated allegations which have been made in connection with the supply of blood derivatives from commercial sources, Armour opened its doors to Dr Peter Jones, Director of the Haemophilia Centre at Newcastle. Dr Jones' brief was to visit a number of Armour Plasmapheresis Centres, to talk with management, staff and donors and to report his findings. It was an essential understanding within this agreement that 'there was nothing to hide' and that the open nature of the visit would allow Dr Jones to report freely on all aspects of the organisation.

"In general, he found 'a first class organisation with a sound commitment to quality control' and that 'the recommendations made at the end of this report are made in the light of this overall judgement'.

"The recommendations made mainly concerned the

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produced by Dr Jones. Dr Jones in his statement says although he had a copy of that report and I think referred to it or produced it with his personal draft record, it's not a visit he made and on further investigation that appears to be correct. So our note is wrong to suggest that that was a visit undertaken by Dr Jones or a report prepared by Dr Jones.

There is a document that Dr Jones has provided to the Inquiry which suggests further contact with Robert Taub, who was the name you will have seen from the Paris visit in 1979. There is what appears to be the record of a telephone conversation in April 1985 which amongst other matters records use by Travenol of plasmapheresis centres outside the US, including in Lesotho, and of course the actions of other pharmaceutical companies outside of the US.

We've given the reference to that in our note, I'm not going to go to it now. It is not clear from the document if it's a record of a telephone call between Mr Taub and Dr Jones or a record of a call between Mr Taub and somebody else. It's certainly consistent with it being authored by Dr Jones but it's not clear on the face of the document, but it is a document provided to us by Dr Jones.

In terms of other interactions with

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pharmaceutical companies, I think there's just one other document to refer you to for present purposes. It's CGRA0000607. This is a Cutter document dated 29 July 1986 and it's setting out details of a meeting with Dr Jones on 24 July 1986. It says:

"My meeting with Dr Peter Jones, director of the Newcastle Haemophilia Centre, was most interesting and in the body of this report I have included the major items we discussed and the follow-up actions required."

Then you will see, sir, the first matter refers to "Octa-Pharma" and says this:

"We discussed Dr Jones' involvement in preparing a product profile for the new firm Octa-Pharma. This company which under licence from the New York Blood Center is manufacturing product at the Hagen Transfusion Service in Germany ... is endeavouring to gain accounts in England, France and Germany. Mr Robert Taub, formerly of Travenol and Armour, had asked Dr Jones to prepare a product profile for a fixed fee and Dr Jones had complied. Dr Jones has reservations concerning the Factor VIII product produced at the Hagen Transfusion Service, but feels that the New York Blood Center product produced in the United States is a superior product and offers

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There's then a discussion about Koate HT product. There's a discussion about Koate HS, and then, bottom of the page, there's a reference to something called the *Whole Earth Haemophilia Handbook*. It says:

"We discussed progress Dr Jones has made to date on his handbook titled 'The Whole Earth Haemophilia Handbook' to address the needs of third world countries in establishing haemophilia care. He intends to be the editor ..."

Et cetera.

"No honorariums will be paid and costs for publication should not exceed £8,000. He is endeavouring to establish one or two sponsors for this handbook.

"Personally I feel such a book is needed and therefore found no problem in agreeing to provide him with an initial funding of £4,000. These funds will be sent direct to Dr Jones and will be drawn from the European budget, not from the Cutter UK budget."

Then there is a discussion about recombinant DNA Factor VIII and Koate HT, Koate HS sales.

SIR BRIAN LANGSTAFF: Could we just go back to the first page of this document. Under "Octa-Pharma" down towards the bottom, what is the implication, do you

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the best data on viral inactivation currently available."

Then there is reference to studies, chimp studies by Dr Prince and a viral inactivation study by Drs Horowitz:

"Dr Jones stated that if this product from the New York Blood Center was commercially available in the United Kingdom it would be his number one choice. He is also committed to do clinicals on the Hagan product with virgin patients, but has expressed some reluctance to do so as he does not have full confidence in the Hagen fractionation operation. I have encouraged his concern in this area and also because of previous experiences with the Drs Horowitz and their ability to mould data to their own purposes."

There's then the discussion about the Armour recall and the Cutter rep says this:

"I used the Armour recall to elicit from Dr Jones his attitude concerning sale in the United Kingdom of non-HIV tested Factor VIII preparations. His response was as expected: very firm regarding this subject. He stated that under no circumstance could a responsible company distribute such a product."

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think, of the information, if it is correct, about 10 lines up beginning at the end of one line "he is", and goes on:

"He is also committed to do clinicals on the Hagan product with virgin but has expressed some reluctance to do so as he does not have full confidence in the Hagen fractionation operation."

Is it an implication from that that he had reached an agreement or made a commitment of some sort to give product to patients previously, who had not previously received concentrate, with a product which he thought was less good than others.

MS RICHARDS: Yes. That is what it's saying.

SIR BRIAN LANGSTAFF: Yes. Does he make any comment about that?

MS RICHARDS: I'd need to check that, sir. I cannot recall without checking whether he was specifically asked about this document or not; so I might see if Ms Fraser Butlin can check that while I carry on with the further documents.

There is -- picking up on Octapharma, there is a further document that relates to it at BPLL0003280.

This is a letter from Dr Smith, a chief project scientist at the Plasma Fractionation Laboratory, to Dr Robinson, consultant haematologist at the Regional

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Transfusion Centre in Leeds, and he says this:
 "Thank you for passing on Peter Jones' protocol for clinical trial of NYBC's [I anticipate that is New York Blood Center] (or Octapharma's) SD Factor VIII. I do not know when it was written, but several points are positively misleading or untrue today. Peter attended Dr Savidge's International Workshop on Haemophilia Care in London on 18th and 19th April, and has no excuse to maintain these errors in future."

Then Dr Smith goes on to talk about 8Y, which obviously Dr Smith was closely involved with, and says this:

"8Y is available to Newcastle Haemophilia Centre and, unlike other products heated at 60 [degrees] for 30 [hours], has not been shown to transmit [non-A, non-B hepatitis] and emphatically not HIV -- approximately 800 patients are solely on 8Y or 9A and there have been no seroconversions, even though some of the batches used were made before HIV screening was standard."

Then he, in the following two paragraphs, provides his comments on two further aspects of the draft protocol, and then he says this:

"NYBC SD VIII has been subjected to NANBH trial

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Haemophilia Handbook, and was asked to give details of the work undertaken and the payment received. He says in his statement:

"No recall, I'm afraid. The Whole Earth Book never materialised, no payment was received."

So he wasn't specifically asked the question you've posed, sir, but he was given the document and said he had no recall. He was provided with Jim Smith's letter of 21 April 1988 to Dr Robinson. He says he didn't have a copy of the protocol referred to and it's the first criticism he has seen of it, so he can't comment and he doesn't remember receiving any payment for that work. It's right to note, of course, that Dr Smith's letter was not sent to Dr Jones.

SIR BRIAN LANGSTAFF: What he doesn't remember is the World Handbook, is it, or --

MS RICHARDS: No, he was also asked -- sorry, sir, it's -- if we put it up on screen it might be slightly easier, WITN0841038. If we go to page 76, his attention is drawn to, and he was provided with a copy of, the Cutter document, and his attention is drawn to the fact that he prepared a product profile for the firm Octapharma, and then the second point is about the handbook, and it says:

"In my relation to each, please give details of

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in the US, France and Brazil. The data are of uneven quality and fewer than 15 patients have been accrued in the US study at the last report. The *in vitro* and chimp work is beyond reproach, but Peter Jones should feel embarrassed by his flimsy grounds for concluding that he has no safe alternative.

"His proposed trial does not meet all ISTH recommendations, and he will be participating in this trial, knowing that a rather safe national product is the subject of a well-publicised and impeccably designed clinical trial, in the hands of two of the most experienced HCDs in the UK.

"Your Scarborough haematologist might like to know what he is lending his patients and support to."

So that's Dr Smith's firm views being expressed in that letter about the Octapharma clinical trial protocol.

There's one further document I want to refer to, but before doing so, I'm just going to check and see if we have anything from Dr Jones in his statement about those documents. I don't think he was asked specifically about some of the matters set out in the first document. He was provided with the document and his attention was drawn to the reference to the product profile and to the funding for the *Whole Earth*

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the work undertaken and the payment received?"

He says "no recall", so:

"Again, no recall I am afraid."

So he was asked about his work in putting together a product profile but not the more detailed question that you've posed, sir.

SIR BRIAN LANGSTAFF: Yes. The question really is what he said to Jack Wood as noted and as, if it's noted correctly and bear in mind that as he may well have had an interest in promoting his own product, then there would be a very clear admission of some form of conflict of interest. At least it would be an inference.

MS RICHARDS: Yes.

SIR BRIAN LANGSTAFF: Unfortunately, Dr Jones is in no position to deal with that or answer it, so I'll have to just make my own mind up about it. Yes, thank you very much.

MS RICHARDS: The last matter I want to deal with is to draw out some of Dr Jones' own words in a radio programme he participated in called *The Reunion*.

Soumik, it's MDIA0000088.

Sir, you will see this is "Unedited transcript of *The Reunion: Contaminated Blood*", and there's a note from the producer to say:

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1 "The Reunion is a Radio 4 discussion programme
2 that brings together a group of people who were all
3 closely involved in an event from recent history to
4 share their memories."

5 We can see the participants from the bottom of
6 the page and we can see they include Mr Watters, but
7 they included Dr Peter Jones, they included
8 Colette Wintle, from whom the Inquiry has obviously
9 heard, Janette Johnson, whose son Graham contracted
10 AIDS and died aged 15, and a patient referred to as
11 "John", who had been infected with AIDS and HCV as
12 a teenager.

13 If we go, first of all, Soumik, to page 13, we
14 can see in the question from SM -- that's Sue
15 MacGregor, the presenter -- to Dr Jones, she says
16 this:

17 "Peter Jones, how early were you aware that
18 there were dangers in the -- some of the blood factors
19 that came through?"

20 This is Dr Jones' response:

21 "Right from the very beginning. From the
22 Second World War when blood was of course used as
23 whole blood or albumin, it was well known that there
24 were hepatitis viruses within blood, and we saw
25 patients with abnormal liver function tests from

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1 that the enthusiasm for treatment, as David has said,
2 overcame that. The other thing that one has to
3 realise is that haemophilia and especially haemophilia
4 carriership which is symptomatic like Colette, is
5 terribly rare. We're dealing in terms of AIDS later
6 with 1,200 patients out of a UK population of what,
7 56 million? So knowledge amongst medical staff,
8 general medical staff who aren't specialised in the
9 subject -- the lack of knowledge among them is very
10 great ..."

11 Ms Wintle refers to the fact that she was
12 talking about the knowledge of haematologists not
13 general doctors and if we go further down the page
14 Dr Jones says this:

15 "... they should have known [as in
16 haematologists]. And you should have been warned. In
17 the concentrates in particular, there was a leaflet in
18 every -- with every bottle, and all those leaflets
19 from a very early stage stated there was a risk of
20 hepatitis."

21 Ms Wintle made the point she didn't get to see
22 the bottles or labels.

23 If we then go on to page 18, and we look in the
24 top half of the page at Sue MacGregor's observation,
25 she says this:

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1 a very early age."

2 Then he talks about an answer that John had
3 given and says this:

4 "But if I could add one thing, the jump which
5 John has described was from cryoprecipitate to
6 concentrate, and the great thing that that did was to
7 allow home therapy. So families could treat their
8 children at home instead of having to go into
9 hospital."

10 If we go over the page, please, and we look at
11 the bottom half of the page, we have CW, that's
12 Colette Wintle, referring to patients not being told
13 of issues relating to hepatitis:

14 "... they weren't advised that there was any
15 risk at any point, and nor were the parents of
16 children."

17 The presenter says this:

18 "It would seem that not only hospital staff
19 were ignorant, because the doctors didn't tell them,
20 Peter Jones."

21 Top of the next page, this is Dr Jones'
22 response:

23 "Not in our experience, as I'm sure you'd
24 expect me to say. The hepatitis risk was considered
25 to be so small, and the haemophilia risk so great,

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1 "We should at this stage, perhaps, Peter Jones,
2 make it clear that the way blood was donated in the
3 United States and in the UK was completely different.
4 In the US you were paid to give blood, and in this
5 country it's all done by volunteers. This proved
6 eventually to become very significant."

7 Answer from Dr Jones:

8 "It was very significant indeed. We know
9 perfectly well, historically, that donors who are
10 altruistic as in the United Kingdom will very rarely
11 carry the sort of viruses that somebody who is being
12 paid in the United States and as you heard from the
13 'World in Action' clip earlier, these are, some of
14 them, drug addicts, alcoholics, skid row donors making
15 the only money they can out of giving their blood.
16 That's where the viruses come in, and then as John has
17 said, the blood has to be pooled, the plasma has to be
18 pooled in order to produce enough Factor VIII. So
19 yes, there is a great difference between the two."

20 Pausing there, you may no doubt wish to
21 contrast that with Dr Jones' own comments in the
22 Northumbrian branch of The Haemophilia Society's
23 spring 1976 newsletter, when he commented to rather
24 different effect on the World in Action programme.

25 If we go over the page to page -- two pages

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1 please to page 20, and if we look at the bottom half
2 of the page, we can see -- so what's then recorded or
3 played in The Reunion is a recording from an earlier
4 Panorama programme from the 1980s. So where it says
5 "PJ on recording" that's Dr Jones as recorded in the
6 Panorama programme from the 1980s and it records
7 Dr Jones then saying:

8 "We had to, we had no choice, this is a --
9 I mean in retrospect again, this a catch-22
10 situation --"

11 Then it looks like Sue MacGregor says:

12 "This is you defending Factor VIII.

13 Dr Jones on the Panorama recording:

14 "-- we either imported or we didn't treat
15 haemophiliacs, and if you look at haemophiliacs in
16 developing countries that have no Factor VIII, it is
17 appalling. I mean two thirds of them are dead before
18 they reach their third decade and the rest of them are
19 lucky to survive without really severe and painful
20 arthritis."

21 Of course, there's no consideration there of
22 the role of cryoprecipitate.

23 Then, if we go to the next page, we see, top
24 half of the page, this is still the recording so this
25 is something being said by Dr Geoffrey Savidge, and

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1 Dr Jones says this:

2 "It's easy to talk in retrospect. With respect
3 to Colette, we did advise all our patients and we did
4 have informed consent, and I have the book where the
5 nurses rigorously recorded the names of the patients
6 and the date that they gave their consent for the
7 testing. And we followed up those patients, the
8 children every three months and the adults every six
9 months, and they were always tested for liver
10 function. So everybody, patients and staff, knew the
11 status of the liver function which reflected the
12 hepatitis virus."

13 I should say we have asked about this book and
14 it appears it's no longer in existence or available.

15 Then if we go on to page 44 please, Soumik.

16 Pick it up halfway down the page, there is
17 a discussion about publicity regarding the spread of
18 AIDS in the 1980s. Sue MacGregor says:

19 "It doesn't sound as if there was a very good
20 publicity about this at the time."

21 Dr Jones:

22 "It was lousy. From the point of view of the
23 Department of Health, we likened them to hermit crabs.
24 They'd come out and show themselves when they had
25 something to say and then they'd disappear back into

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1 then "PJ on recording", so this is Dr Jones:

2 "Well, if you take it at its lowest level, a
3 hundred are going to get AIDS. If you take it at the
4 highest level, which is the level for male homosexuals
5 in the United States, then perhaps two hundred of them
6 will get AIDS."

7 Then Sue MacGregor says:

8 "Well, Peter Jones, that was the younger you
9 speaking. And we now know it was six times that
10 number."

11 He's asked to comment on that. Dr Jones says
12 this:

13 "No, it was slow progress. The first case, the
14 first testing from the discovery of the virus in 1981,
15 was in 1982, and we now know that most of the
16 haemophilia population who were infected were infected
17 in the mid- to late 70s [Dr Jones accepts in his
18 witness statement that that's not correct]. So in
19 fact the disease was ahead of the testing, and as the
20 disease emerged in the hospitals and clinics, we saw
21 the true extent of the disease."

22 If we go on then to page 24, and I should say
23 the context for this is the other participants,
24 including Ms Wintle having talked about the importance
25 of the patients knowing if there was a risk, and then

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1 their shells."

2 Then he refers to the AIDS conference organised
3 in Newcastle in 1986 by Dr Jones, and talks about the
4 scale of media intrusion, and he says this:

5 "I used to take between forty and fifty phone
6 calls a night at the height of this, from newspapers,
7 particularly in the United Kingdom --"

8 If we go on then to page 53, we can see,
9 picking it up about a third of the way down the
10 page -- well, first of all, Dr Jones says there's no
11 alternative, and then Colette Wintle saying there was,
12 and Dr Jones saying:

13 "There was no alternative but plasma and
14 cryoprecipitate until a drug called DDAVP ... came
15 in."

16 Then he talks about DDAVP in these terms:

17 "... the first worry about this drug, which is
18 also called Desmopressin, is that you could only give
19 it once. So, you were in a dilemma again. We now
20 know that's not true, but you were in a dilemma again
21 about what that once was to be: was it to be a brain
22 haemorrhage, was it to be surgery, was it to be dental
23 extractions? So you were in difficulty again. But
24 the mild patients, certainly, if we'd known about
25 DDAVP earlier, should have been treated with DDAVP."

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1 Not entirely clear what he's talking about
2 there or what time period he's referring to because
3 we've obviously heard evidence from others that DDAVP
4 was in regular use from around 1978 onwards.

5 If we go over the page -- sorry, actually
6 I should pick it up -- sorry, Soumik, sticking with
7 this page -- bottom of the page we have Ms Wintle
8 saying:

9 "... I'm saying they shouldn't have been
10 exposed to commercial US plasma ... on the scale that
11 they were. Particularly --"

12 Dr Jones says:

13 "All I can say --"

14 If we go over the page Ms Wintle says:

15 "-- with the risks that were known."

16 Dr Jones says this:

17 "-- All I can say is that I entirely agree with
18 you. We exposed one of our patients to a concentrate
19 from America when he was, I think, seven. And the
20 reason for that exposure was that the family, in
21 particular, wanted him on home therapy. And so did
22 we. And that later transpired to have given that
23 patient HIV, and he died when, I think, he was
24 11 years old. So in retrospect, that was a wrong
25 decision and we shouldn't have put him on home

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1 in the care of our patients. None of these things
2 have been found in the way that Colette had suggested.
3 None of them have turned up, like the Inquiry in
4 Scotland, anything to suggest negligence and I can't
5 stress that more."

6 Then he says this:

7 "We're faced now with a small group of patients
8 and families who are still extremely angry for obvious
9 reasons, but within those groups are people who are so
10 self-centred, and so manipulative that they can
11 continue to pretend there is going to be a favourable
12 response to compensation. And on their side,
13 unfortunately, they have a gullible press who love
14 human stories. So this makes, this makes life --"

15 Then there's a question from Sue MacGregor
16 about compensation, and Dr Jones says:

17 "I don't think that they will ever receive --
18 what is the right sort of compensation?"

19 Sue MacGregor: "You mean it's impossible to
20 judge."

21 Dr Jones: "Well I think that within the society
22 of the United Kingdom it is. David and I called it
23 recompense in order to try to get what led to the
24 Macfarlane Trust ...

25 "Which was some form of recompense and we used

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1 therapy."

2 Then if we go on to page 66, this is the last
3 set of extracts, this and the following pages. I'm
4 sorry I should pick it up at the bottom of page 62,
5 please, Soumik. So the bottom of the previous page.

6 We can see that there is a long or relatively
7 long statement by Ms Wintle and then Sue MacGregor at
8 the bottom of the page says:

9 "Peter Jones, do you accept that criticism of
10 doctors?"

11 Dr Jones says:

12 "-- No I don't. No, no ..."

13 Sue MacGregor says:

14 "-- Of actually people being given -- it was
15 not inadvertent, people knew that the blood plasma was
16 infected."

17 Top of the next page, Dr Jones says this:

18 "That is totally wrong. I've been through
19 two years while I was working, I retired 16 years ago,
20 of litigation for -- against the Health Authority with
21 the lawyers. And then I worked for a while with the
22 Irish Haemophilia Society and their litigation against
23 the Irish Government. And then more recently we've
24 been through three more years with the General Medical
25 Council of being accused of all sorts of malpractice

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1 it to treat problems rather than patients."

2 He's then asked how much doctors were affected
3 by the arguments and distressing things that happened
4 to their patients and, over the page, he says at the
5 top:

6 "Very badly, there are rumours of suicides,
7 there's certainly depression ...my nursing staff --
8 very badly affected. And the reason we've come
9 through it is because we work as teams and support
10 each other, and we've got strong families."

11 Then Ms Wintle makes an observation that that
12 pales into insignificance compared to what happened to
13 the haemophilia community.

14 Ms Wintle then raises the Archer Inquiry and,
15 if we go to the next page, this is what Dr Jones has
16 to say:

17 "I'm sorry to have to say, but in my opinion
18 the Archer Report was useless. The evidence that was
19 given was non-adversarial, it was not taken under
20 oath, it wasn't a legal process and I know from
21 experience that some people who gave evidence at that
22 inquiry lied."

23 He's asked why they did, and he said this:

24 "Because they're so angry. And in the case of
25 one person that I know, this is entirely self-centred

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and acquisitive -- they want money. You can have all the reasons that Colette gives for why they want money, but they're now doing harm not only to themselves, in my opinion, but also to the new generation of people with haemophilia who are growing up with their families and they're faced at all meetings of The Haemophilia Society with this anger. And it should be dissipated by now."

Then he's asked by Sue MacGregor if they're not to get money what would they suggest, and she asks about an apology. He says:

"Well of course they should have an apology. We've apologised and apologised and apologised, and David Cameron apologised twice."

Ms Wintle's intervention:

"Yes, but he did say for something that should not have happened."

Dr Jones: "Well of course it shouldn't have happened but it did!"

Dr Jones was asked about his comments in The Reunion programme when he made his witness statement. If we could go, please, to WITN0841005 and if we go to page 49, please, he says this (so this is in his statement to the Inquiry):

"... I do not accept the criticism of doctors

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you will see he said, "Oh, well, it's confidential because of medical records".

SIR BRIAN LANGSTAFF: Yes, it's "I know what's in the records but I'm not allowed to say".

MS RICHARDS: Yes. I don't think he was asked about the particular comment about a fishing exploration. He was asked again, when he was asked to provide a second statement:

"Please identify the evidence given to Archer that you claim was untrue."

Again, he declined to answer, saying:

"I'm unable to provide further information as this is comprised in confidential clinical records."

But no further information, sir, on that point.

SIR BRIAN LANGSTAFF: The reason for him and whoever else it was who was asked but did not attend to give evidence at the Archer Inquiry that they didn't participate because someone, unnamed, said without there being any further detail that it was a "fishing exploration". Quite a bold claim. It's a strange reason to give for not participating. That's comment on my part but yes. Thank you.

MS RICHARDS: Sir, that completes the presentation for today's purposes. I'm conscious that in relation to Newcastle and Dr Jones there's obviously a wealth of

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especially with regard to the counselling of patients and their families and to informed consent. I do believe that the anger, which is a normal part of the grieving process, should have reduced over time and that the continued campaigning using false information can only do harm to the new generation of patients and their families. My record shows that I was an active campaigner for compensation myself ... and I therefore suggest that I do know what I am talking about."

As to the question relating to lies (that's the allegation he made in The Reunion that people told lies to the Archer Inquiry), he says this:

"... the medical record involved contains evidence of these but is of course confidential.

"With regard to the Archer Inquiry, I stand by my comment for the reasons stated in the transcript. My colleagues and I were informed at an early stage that it was a 'fishing exploration', which is why we did not participate. In addition, there was no information on funding."

SIR BRIAN LANGSTAFF: Just pausing there, does he ever say or was he ever asked who told him and what he says are his colleagues that Archer was a fishing exploration?

MS RICHARDS: No. He was asked to provide details of what he said were the lies told to the Archer Inquiry and

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documentation available and I've only referred to some of it. Of course, all of it is material that can and will be considered by the Inquiry and if there are further documents which any Core Participant or their recognised legal representative wants to draw to the attention of the Inquiry, they are extremely welcome to do so and, no doubt in due course, there will be opportunities for submissions to be made about the centre and the clinicians in question.

SIR BRIAN LANGSTAFF: Could you just do one thing for me before you wrap this up entirely. I just want to go back to *AIDS and the Blood*, RLIT0000046.

You took me there to -- it's RLIT0000046, Soumik -- you took me there to page 7. I think that is internal page 7, so it may be 11 --

MS RICHARDS: Page 9, I think, electronically.

SIR BRIAN LANGSTAFF: Can we just look at what he says the present position there is at the bottom of the page.

MS RICHARDS: In terms of the figures?

SIR BRIAN LANGSTAFF: Yes. At that stage, he is recording three haemophiliacs but this was published in February '85 first time.

MS RICHARDS: Yes, and it's certainly referred to, presumably in unpublished form, in documents from 1984. I think there's a discussion about whether

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1 sending copies of it to members will be funded or
 2 facilitated by The Haemophilia Society. So it would
 3 almost certainly have been written, I think, in 1984.
 4 **SIR BRIAN LANGSTAFF:** So it's plainly written in the year
 5 before there was a testing in Newcastle and, in
 6 Newcastle, am I right in remembering that you told me
 7 that out of 99 tests I think done on the more serious
 8 or more severe haemophilia A patients there were 76?
 9 **MS RICHARDS:** Yes, I think that's right. We also have the
 10 figures for those infected who were mild or moderate,
 11 but yes.
 12 **SIR BRIAN LANGSTAFF:** That tells us how many positive
 13 tests there were, but it doesn't tell us how many
 14 actual cases of AIDS there were amongst them.
 15 **MS RICHARDS:** No. Of course that wasn't known at the time
 16 of testing. There may be later publications, I think
 17 there probably are, which refer to -- for example,
 18 Dr Jones refers, I think perhaps later in '85 and in
 19 '86 to cases of lymphoma. You will recall he wanted
 20 to know why it seemed that a number of the patients in
 21 Newcastle seemed to be in a worse position than
 22 elsewhere. So a very substantially larger number than
 23 the kind of figures given here of the Newcastle
 24 patients condition deteriorated and developed AIDS.
 25 **SIR BRIAN LANGSTAFF:** But there's nothing said even in the

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1 **MS RICHARDS:** Thank you, sir.
 2 (4.03 pm)
 3 (Adjourned until 10.00 am the following day)

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1 foreword.
 2 **MS RICHARDS:** I would have to check the whole book,
 3 I think, in order to give an accurate answer to that.
 4 **SIR BRIAN LANGSTAFF:** Perhaps you could let me know in due
 5 course on that. I can look myself but perhaps so can
 6 others. It will be a question of forming a view as to
 7 whether it merited some form of updating even before
 8 publication, given the dramatic change there had been
 9 at the end of 1984.
 10 **MS RICHARDS:** Yes.
 11 **SIR BRIAN LANGSTAFF:** That's all that I wanted to ask.
 12 **MS RICHARDS:** We resume with the continued evidence of
 13 Mr Watters tomorrow at 10.00 am.
 14 **SIR BRIAN LANGSTAFF:** Yes. Just before we part, those who
 15 have an interest in the trusts and schemes should
 16 know, I believe, that on the website today the
 17 timetable for the four weeks during which we will be
 18 hearing evidence on trusts and schemes beginning on
 19 Tuesday 23 February, that's been published today.
 20 **MS RICHARDS:** I think it was published yesterday in fact,
 21 sir.
 22 **SIR BRIAN LANGSTAFF:** Published yesterday. So anyone who
 23 wishes to know what is happening with the trusts and
 24 schemes, they will see that the details are there.
 25 Thank you very much. 10 o'clock tomorrow.

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