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(9.30 am)

THE CHAIRMAN: We seem to be complete. Mobile phones turned off. Our first witness is Lord Jenkin.

THE RIGHT HONOURABLE LORD JENKIN (called)

THE CHAIRMAN: Thank you very much for coming, Lord Jenkin.

We have your statement, so we can take that as read, I take it.

A. It seemed to be rather a waste of time to read it all out to you.

THE CHAIRMAN: Yes, indeed. You became Secretary of State in 1979 and went through to 1981 when you were moved to another department?

A. Yes, September 1981, yes.

THE CHAIRMAN: And I think your Minister of State was Dr Gerard Vaughan?

A. Yes.

THE CHAIRMAN: And you were content to leave the day-to-day administration in relation to health to him?

A. Some issues on health. He is a doctor.

THE CHAIRMAN: Yes.

A. And he knew a lot more of course about the medical aspects than I ever would and particularly he was knowledgeable about this subject. And I was, therefore, very happy to delegate to him the day-to-day conduct of

1 the department's affairs on this matter provided he kept
2 me in touch with anything important, and particularly if
3 there were going to be any parliamentary repercussions,
4 parliamentary questions or whatever, and I met him from
5 time to time and we went through the papers.

6 I did ask my private secretary to make sure that all
7 the important papers did come across my desk and they
8 were in my red box and I was able to skim through them.
9 But generally very happy to leave that to Dr Vaughan, as
10 he then was. He later became Sir Gerard.

11 THE CHAIRMAN: Sadly he cannot give evidence.

12 A. No, he was much missed.

13 THE CHAIRMAN: We appreciate this was quite a long time ago.

14 If you tell us there is something you cannot remember we
15 fully understand. But could you help us, how often did
16 issues relating to infected blood come across your desk
17 then, was it something that was happening ongoing or was
18 it just occasionally?

19 A. The answer is it was of course an ongoing problem and
20 with certainly an ongoing concern by the medical
21 officers and others in the department, but that did not
22 necessarily mean that I was dealing with it on a daily
23 basis. On the contrary, my recollection is very clearly
24 that from time to time, which might have perhaps been
25 once or twice a month, some particular development or

1 some particular paper would be put in my box.

2 THE CHAIRMAN: Relating to infected blood?

3 A. Relating to the subject.

4 THE CHAIRMAN: Yes, I see.

5 A. There were lots of other papers.

6 THE CHAIRMAN: Of course.

7 A. And I would therefore perhaps then feel it necessary to

8 have a brief word with Gerry Vaughan to see whether he

9 was happy to continue to deal with that and was dealing

10 with it satisfactorily. And I got the impression that

11 with the concern of the department, which was undoubted,

12 because it was then seen to be quite a serious

13 problem -- perhaps not as serious as it subsequently

14 turned out to be --

15 THE CHAIRMAN: Of course.

16 A. But not a happy story, and we were very concerned to try

17 and make sure that the Blood Transfusion Service could

18 be relied upon again, because at that point there was

19 I think quite a shadow hanging over the BTS.

20 THE CHAIRMAN: Yes, I see. Clearly the first thing we are

21 trying to get a picture of was how high profile this was

22 in the department. So it did come to the desks of

23 senior ministers, you said something like twice a month

24 in your case?

25 A. I am sorry, you have already recognised it was rather

1 a long time ago.

2 THE CHAIRMAN: Yes, of course.

3 A. But that is the impression that I remember, but I do
4 remember (a) it was a continuing concern and there was
5 members of the Chief Medical Officer's staff who were
6 certainly involved in this on a continuing basis, and
7 they were consulting ministers as necessary and keeping
8 us informed so that we would not be caught by surprise.

9 THE CHAIRMAN: Yes, I see. You were aware then about
10 infected blood from -- you were saying, were you?

11 A. No, you are quite right. I had been told that the Blood
12 Transfusion Service was not self-sufficient and that
13 they had to buy what was generally referred to as blood
14 products, had to buy them from other sources, and one of
15 them certainly was the United States. At that stage
16 I had no idea where it was coming from in the United
17 States. I assumed they had a source which they could
18 rely on.

19 THE CHAIRMAN: Yes, I see. But were you aware so far as you
20 remember whether it was known that the infected blood
21 was substantially the blood coming from America?

22 A. I think we had become aware that that was probable.
23 I think the source by then had been identified and,
24 therefore, must have been turned off, nobody would
25 continue to import blood products they knew to be

1 contaminated, but I don't think at that stage there was
2 any awareness about the contamination relating to HIV or
3 what has subsequently become known as Hepatitis C.

4 THE CHAIRMAN: Not even Hepatitis C?

5 A. No, I don't think -- I have since seen -- we can perhaps
6 come to this -- the papers which demonstrates that the
7 department was certainly very well aware of what was at
8 that stage being called non-A, non-B hepatitis, but as
9 I have always understood at that stage it was regarded
10 as a very minor condition and perhaps not many sufferers
11 would ever in fact have any symptoms at all. They now
12 know it is different.

13 THE CHAIRMAN: Of course. There was no clear awareness of
14 infection relating to HIV as far as you remember?

15 A. That all arrived later. My successor, Norman Fowler,
16 now Lord Fowler, he had to pick up the baton on HIV
17 because it had become then a major international
18 scourge, and he devoted a huge amount of time to that,
19 and of course it then became apparent that some of the
20 sufferers of HIV had had contaminated blood.

21 THE CHAIRMAN: You have mentioned the question of
22 self-sufficiency in this country. Were you aware of the
23 debate which had taken place earlier as to the
24 importance of self-sufficiency?

25 A. I don't think at that stage it was regarded as an

1 important factor. If the NHS, if the Blood Transfusion
2 Service could get an acceptable blood product from
3 another source, it was felt that that was a way of
4 keeping the NHS supplied with blood.

5 THE CHAIRMAN: Yes, I see.

6 A. I don't think there was at that stage a policy of
7 seeking to become self-sufficient.

8 THE CHAIRMAN: I don't know whether -- I am sorry to press
9 you on matters which, as you say, are a long time ago.
10 I wonder whether I could evoke any memories. On the one
11 side of the debate it seems to have been said: we ought
12 to be self-sufficient partly because of the danger of
13 infected products from abroad and partly officials seem
14 to have been concerned about the savings in money,
15 because the imported products were expensive.

16 A. Yes, I think there was an awareness that there needed to
17 be an enhanced programme of attracting volunteers to
18 give blood, and I think the Blood Transfusion Service
19 over the years has had a remarkably fine record --

20 THE CHAIRMAN: Indeed.

21 A. -- in securing blood supplies, but I think it was only
22 later -- I don't recollect there being -- maybe my
23 memory is at fault but I don't recollect there being at
24 that stage a strong policy imperative that this country
25 should become self-sufficient.

1 THE CHAIRMAN: Nor of anyone saying on the other side of the
2 argument: we must be careful of overriding clinical
3 freedom?

4 A. Well, that is always an argument to which ministers have
5 to pay very close regard, but I don't think any doctor
6 would claim the freedom to administer contaminated
7 blood --

8 THE CHAIRMAN: Indeed.

9 A. -- would be part of his professional duty.

10 THE CHAIRMAN: Of course. I wonder whether you could help
11 us on this because we have not had any evidence on it at
12 the moment. For a product to be sold or administered in
13 this country requires a licence under the Medicines Act?

14 A. I believe so, yes.

15 THE CHAIRMAN: And the licensing authority is the Secretary
16 of State. But I think we have rather gathered from the
17 documents that the Secretary of State, as you say, would
18 be at the mercy of expert committees and that it was in
19 fact really then at committee level. Can you remember
20 anything about that?

21 A. No, I think one had occasional arguments about new drugs
22 and so on, things that are now handled by NICE, but
23 these are always highly technical questions with very
24 considerable medical expertise necessary to make
25 a judgment, and it may well be that Sir Gerard Vaughan

1 would have had some understanding but certainly I would
2 not have had. I am not a scientist and I am not
3 a doctor and I would rely entirely on the advice of the
4 Chief Medical Officer and his staff, and my recollection
5 is that I was very well served by them. They had an
6 excellent team. And I had very good relations with them
7 and I think it was very important that that should be
8 so.

9 THE CHAIRMAN: Certainly. But -- again if you do not
10 remember please say so -- there seems to have been
11 a discussion at one point as to whether the risky
12 products should be admitted because we were not
13 self-sufficient at the cost of denying some people
14 treatment.

15 A. I have no recollection of that but I would say that it
16 certainly would not have surprised me that that would be
17 so, because one was aware that some contaminated blood
18 products had been acquired from overseas and clearly it
19 was desirable to make sure that that should never happen
20 again.

21 THE CHAIRMAN: Yes. Just one other matter, if I may.
22 During your period as Secretary of State it seems that
23 there had been an increase in the products of blood
24 transfusions in this country, an increase in the supply
25 of plasma, but that the laboratory at Elstree wasn't

Document *W.A. Gunning* *his understanding*
esp *Comp package*

1 capable of manufacturing that amount. And then in
2 1979 -- I think you took office in about May, did you?
3 A. June, I think.
4 THE CHAIRMAN: June, was it?
5 A. Yes. When we won the election.
6 THE CHAIRMAN: And it was just about that time, I think,
7 that it was discovered that Elstree was defective in
8 hygiene.
9 A. Yes. Now I do remember -- in a sense you have reminded
10 me of this -- there was a considerable amount of
11 discussion about whether the laboratory at Elstree
12 should continue to perform this duty, and indeed my
13 recollection is that subsequently it was closed down.
14 Certainly this role was transferred to other
15 laboratories no doubt in universities and elsewhere.
16 I am afraid I have no recollection of the details but it
17 certainly was an argument, was a matter for discussion.
18 THE CHAIRMAN: The problem being at that time there was
19 really no other facility certainly in England although
20 there was probably one in Scotland. You do not remember
21 that?
22 A. I'm afraid I don't because I think what was felt was
23 that Elstree had, as it were, out-run its limitations of
24 what it could do and that it was necessary to build up
25 some other facility for testing blood, and of course in

1 those days some of the tests haven't even been devised,
2 which is why the contaminants were allowed to run on for
3 some time.

4 THE CHAIRMAN: Indeed. I wonder whether we could then move
5 on. Subsequently, after you had left the department,
6 and I suspect after -- I don't know whether you were
7 still in Government -- you were approached about the
8 problems which had arisen from infected blood?

9 A. This was long after I left the department and indeed
10 long after I had left the Government. I see that you
11 will be seeing David Amess shortly.

12 THE CHAIRMAN: Yes.

13 A. He was chairman of the hepatitis all party group. And
14 I am not quite sure why -- you may ask him -- but he
15 persuaded me to go along to one of their meetings and
16 I was quite horrified because I had had absolutely no
17 contact with this subject at all since I had left the
18 department. One has new departments to run and you
19 can't go on running the old one.

20 THE CHAIRMAN: No, indeed.

21 A. And I was quite horrified to find out how widespread the
22 contamination had been and particularly the emergence of
23 Hepatitis C as a very serious scourge for the patients
24 who had been contaminated.

25 THE CHAIRMAN: Indeed.

1 A. And I began to become interested at that stage and it
2 was subsequently that one of the sufferers, I think
3 I mentioned him in my report, [GRO-A] from Scotland,
4 said, "But look, you were Secretary of State at the
5 critical time, could you go back and look at the papers
6 and see if you can find any evidence which might support
7 our case for some form of entitlement to compensation?"

8 And I felt it was a duty I owed them because it is
9 something that ministers can do. And I have spelt out
10 the somewhat chequered history of my attempts to get at
11 that through the department. And eventually I went to
12 see the permanent secretary, and perhaps, looking back
13 on it, I should have gone to him first, that is the
14 normal channel. I went to the minister in the House of
15 Lords, Lord Warner, and that wasn't very successful.

16 But when I went to see the permanent secretary,
17 Sir Nigel Crisp, now Lord Crisp, we got the thing back
18 on the right track. But it was then that Sir Nigel --
19 and I remember his words very clearly and I quoted them
20 in my statement:

21 "Sir Nigel made it clear to me that all the files
22 that bore upon the issue of contaminated blood products
23 had been destroyed."

24 And he said the reason was they had settled the HIV
25 cases, compensation had been paid, and that it therefore

1 had not been thought necessary to keep the files. And
2 I rather hung my further thoughts on that, that it had
3 been a conscious decision not to keep the files because
4 it was thought there would be no further purpose.

5 So what I have been doing since then is to ascertain
6 and to satisfy myself, and I am satisfied beyond all
7 doubt, that from the middle of the 1980s the department
8 was very well aware of non-A, non-B hepatitis, as it has
9 become Hepatitis C, and that they were well aware that
10 that was one of the consequences of the transfusion of
11 contaminated blood.

12 My immediate request -- reaction to Sir Nigel was,
13 "But surely they knew that there were these other
14 sufferers suffering with hepatitis who had suffered in
15 exactly the same way as the HIV. Why just because you
16 have settled the HIV cases was it decided to destroy the
17 files?" And Sir Nigel's answer, "I'm afraid that's what
18 happened".

19 Subsequently of course we have been told it was --
20 and I put the word in quotes -- "inadvertent". That was
21 the words that Norman Warner used to me and that is the
22 subsequent explanation that has appeared in the
23 correspondence that you have no doubt heard in evidence.
24 It was a mistake, it was an error, it ought never to
25 have happened..

1 I have been unable to reconcile that statement with
2 what the permanent secretary told me when I first met
3 him, that it was decided not to keep the files.

4 THE CHAIRMAN: I think something may turn on the level at
5 which it was decided, but it may have been decided by
6 someone who should not have taken the decision?

7 A. That was right. It was clear -- I mean he knew I was
8 coming, it took me some weeks to get the appointment
9 with Sir Nigel, who was extremely helpful, very
10 apologetic about the earlier letters that I had which
11 were ridiculous, and he must have been briefed.
12 Somebody told him that. He would not have invented it.
13 I don't know whether you are going to talk to him.

14 THE CHAIRMAN: I think we may have some further evidence on
15 that later. I could perhaps shorten this. Would you
16 have any objection to the whole of that correspondence
17 being made public in our report?

18 A. No.

19 THE CHAIRMAN: If it is relevant.

20 A. No, I think it is very much part of your inquiry and --
21 both the correspondence and the parliamentary questions,
22 because I was pursuing this by this time in the House
23 and I had a series of parliamentary questions, the first
24 of which produced the answer: they were destroyed
25 inadvertently. And I have since pursued this with

1 ministers from time to time, until your inquiry was
2 established, in which case I said: well, over to you.

3 THE CHAIRMAN: Yes, thank you. One other matter; perhaps we
4 can deal with it quite quickly. Mr GRO-A I think has
5 referred to a secret report financed by Westminster or
6 something.

7 A. Yes.

8 THE CHAIRMAN: And it was that that you originally wrote
9 about. Am I right in saying that Lord Warner's first
10 letter said, "We don't know of any documents on any
11 secret report"?

12 A. His first letter, as I have said in my report, was
13 clearly a piece of maladministration by the department
14 for which Sir Nigel subsequently apologised, and it was
15 clear that the impression that that letter had given,
16 that there was nothing that could possibly -- no way
17 that they could possibly find what was being referred
18 to, was actually quite wrong, and that they had some
19 very considerable records. And of course, as you know,
20 the report subsequently turned up in Scotland.

21 THE CHAIRMAN: But I think what -- perhaps this should
22 emerge from the correspondence, but it seems that he
23 wrote back, "We haven't any records relating to this
24 secret report". He did not say -- as you correctly
25 point out -- "But of course we have a lot of other

1 records relating to infected blood".

2 A. Yes.

3 THE CHAIRMAN: And you inferred from that that there were no
4 other records.

5 A. Well, I think the way I put it to Sir Nigel when I went
6 to see him about this was that I had been left with the
7 impression that the department's records were deeply
8 flawed, which turns out not to be the case, that they of
9 course have had a huge amount of paper, much of which,
10 I am sorry, sir, you and your colleagues have had to
11 see.

12 THE CHAIRMAN: Indeed.

13 A. Including this latest enormous batch which
14 Caroline Flint has sent me. ~~But there was never any~~
15 question, the files that have dealt specifically with
16 contaminated blood, and some of these papers I had seen
17 when I was Secretary of State, they no longer existed.

18 THE CHAIRMAN: Yes.

19 A. They did not exist in the department's files.

20 THE CHAIRMAN: No, I follow. We now know that following
21 a further enquiry some of them seem to have re-emerged.

22 A. Some of them have emerged from the department, and that
23 I don't understand, because why didn't they find them
24 first time round? The second lot of course came from,
25 as it were, the counterpart of the department's

1 correspondence, the firms of solicitors, who have been
2 pursuing cases on behalf of clients.

3 THE CHAIRMAN: Yes, a lot of them have been sent to
4 solicitors.

5 A. I should make it clear, the latest batch I have not sat
6 down and looked at, and Lord Turnberg will know I have
7 other preoccupations at the moment, with embryos and
8 tissues and statistics bills and various other things
9 that I am pretty busy with.

10 THE CHAIRMAN: But there is no reason to think now there are
11 any records which you might look at which haven't been
12 made available to you?

13 A. Well, I have to take it on trust from the minister who
14 sent this latest batch, is that this is all that they
15 have been able to find, and Caroline Flint said much of
16 it has already been available to the public under
17 Freedom of Information procedures. And I discussed this
18 with the inquiry's secretary and I said, "Is there any
19 point my looking through the papers?" And he said,
20 "Well, you haven't yet and your officials yet haven't
21 been able to do this so this is future business".

22 THE CHAIRMAN: Yes, I follow that.

23 A. I have not studied those papers.

24 THE CHAIRMAN: No doubt at least we will be asking to see
25 them later.

1 A. Yes.

2 THE CHAIRMAN: Yes, thank you.

3 LORD TURNBERG: I wonder if I could take you back over one
4 of two of those questions. I am sorry to ask you about
5 the distant period when you were in the department, 1979
6 to 1981. You have said that there was a shadow over the
7 Transfusion Service at that time. Can you elaborate on
8 what that was?

9 A. Certainly in the department there was an awareness that
10 the Transfusion Service had bought infected,
11 contaminated, infected blood products, which we have
12 come to talk of as contaminated blood, and that this had
13 been administered to some patients, no doubt many of
14 them haemophiliacs, of course who require regular
15 transfusions. And I think we were well aware that this
16 was certainly not a happy story for the Transfusion
17 Service or for the department, and that is why ministers
18 were pursuing this and trying to find out what could be
19 done to prevent it, prevent it happening.

20 As I say, at that stage there was no test known for
21 Hepatitis C and that, therefore, there was no way of
22 testing a blood donor or a source to see whether it was
23 infected, and yet nevertheless this had happened. But
24 what I had understood at the time was that although
25 Hepatitis A and B are regarded as serious illnesses, at

1 that stage the medical advice was, "Well, Hepatitis C is
2 something infinitely less serious, and indeed the
3 symptoms may never become apparent".

4 As we now know, that was a complete misunderstanding
5 of the situation, but that was the state of medical
6 knowledge at the time, and of course, as I say, we were
7 not at that stage aware of the scourge of HIV.

8 LORD TURNBERG: In practice Hepatitis A is not terribly
9 serious but B certainly is and C presumably was put in
10 the category of an A type infection.

11 A. I would not be in a position to express a view on that.

12 LORD TURNBERG: If it was being recognised in the department
13 that there was something amiss here with contaminated
14 blood, what sort of actions were being taken? Do you
15 have any recollection of that?

16 A. The actions were being taken certainly to step up the
17 testing on blood products and also the testing --

18 LORD TURNBERG: Of Aids.

19 A. -- of ordinary blood donations.

20 LORD TURNBERG: Testing for Aids, presumably.

21 A. Yes, testing for Aids or for any of the other infections
22 that people might have. It is very important if
23 somebody comes along and presents himself at a blood
24 donor centre and they test the blood and say, "I'm
25 sorry, I don't think we can have yours". And I think we

1 were very concerned to make sure as far as possible that
2 we were dealing with sound products.

3 LORD TURNBERG: You suggested that you took the view that
4 they, presumably the Transfusion Service, were sourcing
5 these products from a source they could rely upon.

6 A. I can't -- I have no recollection of that. I mean, they
7 must have been -- they thought they could rely on it.
8 When one has read subsequently what has come out and
9 what the source actually was -- and I refer to this in
10 my statement, namely blood taken from prisoners in
11 American prisons perhaps even without their consent.

12 LORD TURNBERG: Were you aware of that?

13 A. I was absolutely not aware of that at all. All I knew
14 is it had come from an American source.

15 LORD TURNBERG: Was it known in the department, do you
16 think?

17 A. I don't know. You will have to ask them. I think they
18 are mostly dead now.

19 LORD TURNBERG: Of course, recognising then what we know
20 now, we would not be in this position, so the question
21 really is what was recognised in 1979/1981 and how well
22 it was recognised at that time, compared with now. Do
23 you have any feel for that?

24 A. Yes, I think I have a feel for it from the papers -- the
25 departmental papers that I was able to see, and from

1 which I extracted -- and the inquiry has had copies of
2 all those -- a lot of papers showing they were aware of
3 the non-A, non-B hepatitis, research was being done, and
4 there are research reports, committee minutes, there was
5 correspondence, all referring to this.

6 And indeed it has been part of my case, as it were,
7 to say that I find it absolutely astonishing that the
8 contaminated blood files were destroyed when the
9 department knew that this was a possible cause of
10 contaminated blood.

11 LORD TURNBERG: I am really interested in the 1979 to 1981
12 period.

13 A. Yes.

14 LORD TURNBERG: And that is a difficult one because it is
15 a while ago. Non-A, non-B was what was thought of as
16 being an infection. It is not clear whether it was
17 thought of as being a serious infection.

18 A. No, I don't think it was. As I said a few minutes ago,
19 I think the advice we had on that from the Chief Medical
20 Officer and his deputies was that it was nothing like as
21 serious as A and B and indeed in many cases symptoms
22 would not be apparent at all. I seem to remember that
23 being said.

24 LORD TURNBERG: Do you have any recollection of what sort of
25 licensing arrangements were in place in those days?

1 A. Well, I would say that I am sure that the proper
2 licensing arrangements were in place. I had no reason
3 to challenge those. And of course as Lord Archer has
4 said, yes, technically in the name of the Secretary of
5 State, but of course Secretaries of State had nothing
6 whatever to do with that. It was left to the experts in
7 the department.

8 THE CHAIRMAN: Thank you.

9 MS WILLETTTS: Was there a view, Lord Jenkin, that the blood
10 products sourced from the UK were safer or less risky
11 than those sourced from the US or was that not something
12 that was discussed at your level?

13 A. I think we certainly were aware of that, that the well
14 established procedures for testing the blood that was
15 taken from donors before it was put into the Service
16 was -- had on the whole worked pretty well. The Blood
17 Transfusion Service -- I mean, I remember, going back to
18 before the last world war, or certainly during the last
19 world war, in my family my mother and I were encouraged
20 to go and give blood, and we had blood transfusion
21 sessions at school, for those of us who were old enough,
22 and used to do that fairly regularly.

23 THE CHAIRMAN: I used to be a blood donor. My recollection
24 was that it was fairly rigorous. I was once turned away
25 because I had just had hey fever.

1 A. I was asked a question, "Are you suffering from a cold
2 or cough?", or something of that sort. But my
3 impression was that there was a general feeling that the
4 reputation of the Blood Transfusion Service stood very
5 high. It had played a hugely important part in --
6 during the war, and then in the years after the war it
7 was felt that this should be an integral part of the
8 National Health Service. Of course it has since been.

9 MS WILLETTTS: If there were a sense that the UK-sourced
10 products were perhaps more sound than those sourced from
11 abroad, that would possibly then influence the need to
12 try to become more self-sufficient, and this is where
13 the self-sufficiency debate comes in.

14 A. Yes, I don't remember -- and I have to say it does not
15 mean to say it wasn't being written about or thought
16 about -- but I don't remember there having been, as it
17 were, any settled policy of becoming more
18 self-sufficient. In a sense the policy would have been
19 to say: let us make sure that what we buy and use in the
20 Blood Transfusion Service is sound and reliable.

21 MS WILLETTTS: I think Lord Owen may have some views.

22 THE CHAIRMAN: I think we should put this to you. Lord Owen
23 had actually given an undertaking in 1975 that there
24 would be a move towards self-sufficiency as quickly as
25 possible. But that was not mentioned in the department?

1 A. It probably was. It would have been part of the
2 thing -- I don't remember this being a particular
3 feature but then I didn't see everything. I saw the
4 things that might have political significance, that was
5 what I was asking for, whether we were going to get in
6 trouble in Parliament. Questions were being asked and
7 we obviously had to answer those. But I am sure there
8 was all sorts of -- all sorts of activities go on which
9 they don't feel necessary to keep ministers fully
10 informed. You can't do everything.

11 THE CHAIRMAN: I think we have been told that a sum of
12 21 million was allocated immediately, I think in about
13 1979, after the problems at Elstree had become clear, to
14 expand Elstree and clean it up. It was a fairly
15 substantial sum.

16 A. Yes. I think this is probably something that
17 I inherited. What is interesting is that I shadowed the
18 department from 1976 to 1979. I have no recollection
19 now of this problem having been raised with me as
20 a shadow minister at any stage. That isn't to say that
21 it may not have been. I am saying I have no
22 recollection of it being.

23 But what I did find is that when we got into the
24 department there was a problem, and I asked
25 Gerry Vaughan to, as it were, take charge of that

1 particular aspect of the department's work. I felt that
2 given his expertise that was a reasonable way of
3 proceeding.

4 MR MEHAN: Might I ask a quick question. Lord Jenkin, we
5 have heard from a lot of witnesses about closure. Do
6 you have any thoughts about how they can have that
7 closure now?

8 THE CHAIRMAN: Closure of Elstree?

9 MR MEHAN: Closure of the issues.

10 A. I think what I have never understood is why it was felt
11 necessary to bring about closure for those contaminated
12 with HIV and a refusal to bring about closure for those
13 contaminated with Hepatitis C. The department of
14 course, and you have heard about this, has its
15 arrangements for paying some compensation, but without
16 admitting any liability, and yet the basis of the HIV
17 one was that the department had recognised that there
18 was a liability and they were being sued and they
19 settled the cases.

20 THE CHAIRMAN: If I may correct you, the department have
21 never actually admitted liability for either.

22 A. That may well be as a matter of technicality, but the
23 impression I was certainly given by Sir Nigel was that
24 they settled the cases because they felt they would have
25 been held liable.

1 THE CHAIRMAN: They were being sued and they settled the
2 case, yes.

3 A. They settled the case because they felt they would have
4 been held liable in the courts. My immediate reaction
5 was, "What about the Hepatitis C sufferers?" Does
6 that --

7 MR MEHAN: That answers my question. Thank you very much.

8 THE CHAIRMAN: Thank you very much, Lord Jenkin, that has
9 been most helpful. Is there anything further you would
10 want to tell us?

11 A. No, I don't think so, but if you want me to look through
12 the latest set of papers which Caroline Flint has sent
13 me, we have a long recess coming up and I might have
14 time to do that. It is quite a thick bundle.

15 THE CHAIRMAN: Quite a formidable bundle, yes.

16 A. If I can be of any help later on by all means ...

17 THE CHAIRMAN: If it arises we can be in touch again.

18 A. Yes of course.

19 THE CHAIRMAN: Thank you very much, I am most grateful.

20 A. I would just add that I am liberated so I may go the way
21 of many others. Thank you.

22 JENNY WILLOTT (called)

23 THE CHAIRMAN: We have just been handed your statement so
24 I think perhaps rather than attempting to pick things
25 out of it now it would be better if you gave us your

1 evidence in the first instance.

2 A. Yes, what I thought I would do -- that is all sorts
3 of -- that's all sort of background information and
4 a lot more detail than I intend to go into today. A lot
5 of it you probably will have seen or know already.

6 And first of all, thank you very much for inviting
7 me along, letting me come along. I come at this from
8 a very particular perspective. ~~I was elected to~~
9 ~~Parliament only two years ago so I am a very new MP, and~~
10 ~~within a short period of time~~ GRO-A, ~~who is~~
11 ~~a constituent of mine, who is sitting at the back came~~
12 ~~to see me and raised this issue with me.~~

13 And I have to say my initial reaction was: that
14 can't possibly be the case, it can't really be as bad as
15 he is saying it is because -- perhaps it is my naivety
16 on my part but I just didn't think that things like that
17 happened in the UK, and if they did then I thought they
18 were investigated and sorted out as early as possible.
19 So I was really quite taken aback and decided to do
20 digging myself through parliamentary questions and
21 through all the other sources that are available to me
22 as a member of Parliament.

23 And I have to say that I became increasingly
24 frustrated and really quite shocked actually by the
25 behaviour of the Department of Health in terms of their

1 unwillingness to give information and how unhelpful they
2 are when you are trying to get information. A lot of it
3 was done through parliamentary questions, a lot of my
4 questions are answered very late, often over a month
5 late, which I believe is actually a breach of the House
6 of Commons' rules, and often the information given in
7 answer is -- could be said to be misleading, is often
8 incomplete, sometimes they don't answer the questions at
9 all. And it is very, very difficult to get information
10 out of them. I have found, from my perspective as a back
11 bench MP.

12 And it was in contrast -- one of the other issues I
13 have been dealing with as a constituency MP relates to
14 the Department of Work and Pensions. And whilst I often
15 don't agree with -- in fact pretty much always don't
16 agree with what they are telling me, on the whole they
17 are better at providing information than the Department
18 of Health. So I think having the contrast between the
19 two departments has really highlighted for me actually
20 how -- I would even go so far as to say secretive the
21 Department of Health is being in terms of the
22 information that they will provide.

23 What I thought I would do is just highlight a couple
24 of different issues, ~~I think three different issues,~~ as
25 . to where I have had ~~-- on different issues that I have~~

1 ~~been trying to get information on and what their~~
2 ~~response has been.~~

3 ~~The first one was about the Government~~
4 ~~self-sufficiency policy which you were just talking~~
5 about with Lord Jenkin. And because there was quite
6 clearly from the mid 70s, a recognition that paid donors'
7 blood was much more likely to be infected than from
8 voluntary donations, and there was clearly a push
9 towards self-sufficiency. And, as you mentioned
10 earlier, the Government had a stated policy I believe
11 from 1975 on self-sufficiency.

12 THE CHAIRMAN: Yes.

13 A. I put down a series of parliamentary questions about the
14 volume of factor VIII that was being produced in the UK,
15 the volume coming in from outside and how much
16 respectively it cost for the different elements.

17 I put down 16 questions and every single one got the
18 same answer which basically didn't answer it and said in
19 the 1970s and 1980s the Department of Health didn't
20 import any blood products at all from outside the UK.
21 They only started doing it in 1999 as a result of
22 variant CJD, although individual clinicians could import
23 blood products from outside of the UK but they didn't
24 have any records of that centrally.

25 Now, I don't think that's particularly -- how can I

1 say this without being rude -- I don't think it's
2 particularly accurate, in fact one might go as far as
3 saying it was downright wrong, certainly misleading.
4 THE CHAIRMAN: If I may interrupt you, just to see whether
5 there is some misunderstanding here. Were they saying
6 that there wasn't a central purchasing until the 1980s?
7 Because it has always been the case that anyone in this
8 country could buy a product abroad if it was licensed.
9 A. Yes, it does say that. What it says is:

10 "During the 1970 and 1980s the department did not
11 purchase imported blood products. At the time blood
12 products laboratory BPL made plasma products from plasma
13 collected from British blood donors and then from 1999
14 they obtained plasma from the United States."

15 And it says clinicians have always been able to do
16 it directly.

17 What I then found out, doing a bit of digging, is
18 that there was a parliamentary answer that Lord Owen
19 gave when he was minister in the 1970s that actually
20 provides the information as to exactly how much --
21 although they weren't purchasing it directly they were
22 acting as a central unit and coordinating the purchase
23 of blood from overseas, and gives exactly the figures as
24 to how much blood was imported from the US, I think it
25 was November 1973 to the beginning of 1975.

1 So those figures clearly are available in the
2 department and they provided them in the 1970s, and yet
3 they didn't -- they just sort of gloss over that. So
4 actually unless I had done some digging I wouldn't have
5 realised there was any way of finding that information.
6 And they also don't mention anything at all about acting
7 as a sort of coordination point for clinicians
8 purchasing blood.

9 MS WILLETTTS: So they are giving a very theoretical answer,
10 "The Department of Health did not", but they would have
11 known there was another --

12 A. Yes, I think that is fair.

13 MS WILLETTTS: -- purchase hub of some sort.

14 A. Just a very incomplete answer and not even indicating
15 there was something else I should have been asking
16 about, which I think is an unfair way to answer a
17 parliamentary question, it sort of goes against the
18 spirit of the principle really.

19 However, they did reference to academic articles
20 about blood products which were -- and production of in
21 the UK, which were much more useful. It gave the
22 proportions of imported blood and UK-produced
23 factor VIII from the 1970s. So as a result of that
24 I then put in 10 more parliamentary questions trying to
25 find out about the -- what had been done to boost

1 domestic production in the UK to try and achieve
2 self-sufficiency.

3 And this might sound familiar, I got the same answer
4 back to all 10, and again it doesn't answer the
5 question. It basically says they can't give me the
6 answer because of disproportionate cost. I had assumed
7 that since I was asking for financial figures that it
8 would actually not be too difficult to pull those
9 figures out for me as to how much had been spent on
10 boosting production over the years in the Department of
11 Health, but they just say they can't provide those
12 figures at all full stop.

13 Again, I tried to piece it together from other
14 sources, but it could be quite difficult, but I think
15 the evidence does suggest that, despite the fact that
16 the Government did have a self-sufficiency policy, the
17 money or some of the money that was referred to in one
18 of David Owen's parliamentary questions in the 1970s
19 talks about putting money into boosting production of
20 I think it is called -- is it AHG, which is factor VIII,
21 in the 1970s, and then an answer that I got talks about
22 the same amount of money being -- with almost exactly
23 the same wording but talking about it being transferred
24 to the regional transfusion centres to boost blood
25 donations.

1 THE CHAIRMAN: That is what they did in 1975, I think.

2 A. Yes.

3 THE CHAIRMAN: In fact there were two limiting factors,
4 there was the amount of blood being produced from
5 donations and there was the capacity of Elstree to
6 process it.

7 A. Absolutely.

8 THE CHAIRMAN: But the money was put into the donation side,
9 I think.

10 A. Yes, what I understand as well, when looking through the
11 figures, there are some letters I understand from the
12 late 1970s from the regional transfusion directors who
13 are writing to the Department of Health about the fact
14 that Elstree has reached capacity, so they are
15 generating more blood donations but actually there is
16 nothing that can be done with the blood, and it is
17 actually going to waste because they have more than they
18 can actually process.

19 So the department clearly was aware of that, and if
20 the resources weren't being put into Elstree, which
21 I think is quite clear they weren't, at that time
22 anyway, then it shows that the policy isn't
23 necessarily -- wasn't being implemented as it was
24 probably intended to five years earlier.

25 The other area that I have been doing some digging

1 on is around documents that have been destroyed, and as
2 far as I can see there are four different batches of
3 documents that have been destroyed or were thought to
4 have been destroyed.

5 The first one is the documents that the department
6 now says they have recovered from unmarked files or
7 whatever in the basement. The second one is the minutes
8 of the advisory committee on virological safety of
9 blood. The third one is the legal waivers that the
10 department says people signed. And the fourth one
11 are -- and I understand that Lord Owen, his personal
12 papers were destroyed when he moved from that ministry
13 in the 1970s; when he went back to ask for them I
14 understand he was told they had been destroyed.

15 That one I am not going to touch on, but the
16 previous three, the one thing that keeps coming out from
17 the information I get is there seems to be an awful lack
18 of clarity as to how many documents are missing,
19 particularly on the waivers. When you ask one time you
20 get told there are only 20 that they have got in the
21 files. Another time you ask they now say they have 90
22 in the files. The 20 was after they had done a great
23 big hunt through the department to try and find as many
24 as they could, and then they don't do anything and
25 miraculously 70 appear. It seems very unclear as to how

1 many they have got, whether they have any evidence of
2 the other ones at all.

3 I understand that the department -- when documents
4 are destroyed that there is an audit certificate
5 produced of the documents so there is actually a trail
6 that can be pursued of the documents that have been
7 destroyed. I have asked for the certificates for the
8 destruction of the minutes and papers of the advisory
9 committee and they have told me they will not give them
10 to me, so I am currently going through a Freedom of
11 Information request to try and find out those, because
12 that is the only group of papers that they have actually
13 done an investigation into what happened and why they
14 were destroyed and how it happened. And whilst there
15 are some --

16 THE CHAIRMAN: Which committee was this?

17 A. ~~The advisory committee on the virological safety of~~
18 ~~blood.~~ The minutes and the background papers were --
19 that the files -- almost all of them from I think it is
20 1989 to 1994, most of them were destroyed, I think it is
21 four out of the 17 files that are still in existence.
22 The rest were destroyed. Now they did an internal audit
23 into what happened to those papers in 2000. We managed
24 to get a copy of it about a month ago, I think, it took
25 quite a lot of effort to get that audit.

1 THE CHAIRMAN: Under the Freedom of Information Act?

2 A. Yes, I originally found out about it through
3 a parliamentary question and then they basically told me
4 they would release it at some point, so we ended up
5 putting in a Freedom of Information request. And even
6 then, when they said they were going to release it, it
7 then got held up by number 10, we got told it couldn't
8 be given to us because it was currently in number 10
9 awaiting clearance, as it were, so --

10 THE CHAIRMAN: That may simply have been the process: it
11 goes from one department to another?

12 A. It might be, but given that it was a document that was
13 actually done in 2000 it seems a bit extraordinary that
14 it has taken seven years and then it is still going
15 through the process of being cleared.

16 Also it is not a very complete report. The
17 recommendations are okay but actually it effectively
18 says: we don't know why they were destroyed and we don't
19 know who destroyed them but we think it was a mistake
20 and we think it was by somebody junior. And that is
21 pretty much all they say. But at least they did look
22 into that. The other groups of documents that were
23 destroyed they haven't even done investigations into,
24 which I do find quite extraordinary, particularly the
25 legal waivers; I mean, those are legal documents.

1 THE CHAIRMAN: That is rather curious, is it not, the
2 waiver, because if the waivers are lost then it is the
3 department which loses out.

4 A. Absolutely.

5 THE CHAIRMAN: Because the sufferers might then be in
6 a position to bring proceedings and there is nothing to
7 stop them bringing the proceedings.

8 A. It would be very interesting to clarify that point
9 actually because the department is telling sufferers
10 that even if they can't produce the signed waiver they
11 know that if they have received financial support from
12 the Macfarlane Trust they must have signed a waiver. So
13 they are treating people in that category as if they
14 have signed a waiver. I think it would be quite
15 interesting if someone was able to give an opinion as to
16 whether or not that would legally stack up. If the
17 department can't prove that they did sign a waiver, does
18 it still bind them?

19 There are over 1300 waivers that have gone, which is
20 an awful lot of legal documents to lose.

21 The fourth set of documents are these ones that now
22 seem to have been recovered, and I think the -- although
23 it is now -- I think it is now quite clear how many
24 there are that they have recovered and so on, and they
25 are processing them, I think it is quite

1 extraordinary -- this goes back to what Lord Jenkin was
2 saying. He is referring to the same documents, he was
3 told they were destroyed and then they appear. The ones
4 that have come back from the solicitors, the number that
5 they say they have got varies from 610 to 623 depending
6 on who you ask and when, so again --

7 THE CHAIRMAN: It depends on what you count as a document.

8 A. That is true, it could do as well.

9 THE CHAIRMAN: Whether it is one document or two.

10 A. But there is a little bit of lack of clarity around
11 that. But there are 5,000-odd documents which have now
12 been recovered. They never did an investigation as to
13 how they were destroyed. That seems extraordinary
14 because that is an awful lot of documents to go missing.
15 And to not actually do a proper internal investigation,
16 an audit into what happened, where they went -- they
17 might actually have discovered them earlier.

18 And that links into the report they did on
19 self-sufficiency of blood products in the UK, which was
20 supposed to be an exhaustive report based on all the
21 documents they had. They can't have looked very hard if
22 they didn't -- that was written before they discovered
23 these documents, so how hard did they look into all
24 their files if they then discover these 4,000-odd,
25 5,000-odd documents less than a year later?

1 I think it leaves some questions to be asked of the
2 report as to how complete it actually is given that
3 clearly an awful lot of information -- I think there are
4 1,500, over 1,500 documents in this 5,000 that relate to
5 self-sufficiency. So there is clearly an awful lot of
6 information out there which hasn't actually been used in
7 the report. So I think maybe there are questions to be
8 asked around revisiting the information in that report
9 as well.

10 But these documents that they have now recovered,
11 they have said that they want to review them all before
12 they release them. I got told in a parliamentary
13 question last year that they would review all of the
14 documents relating to the period 1970 to 1985 and they
15 would publish the review of all the documents before
16 releasing the documents. When the review was published
17 earlier this year actually all they reviewed was
18 documents relating to non-A, non-B hepatitis for the
19 period 1970 to 1985. And that was 95 documents out of
20 over 5,000.

21 That is the smallest -- they do a breakdown in the
22 report of -- in five-yearly periods, so 70 to 75, 75 to
23 80, and so on, and then break it down into about six or
24 seven different subjects. And they put the proportion
25 of the papers that they hold for each of those subjects

1 for each of those five-yearly periods. And having gone
2 through and added up and done percentages and so on, it
3 is around 95 documents on non-A, non-B hepatitis for
4 that 15-year period, which is by far the smallest number
5 of documents that they could have reviewed. There are
6 nearly 2000 documents on Aids for the same period, for
7 example. There is over 500 that are outside of that
8 time period. 1,500 on self-sufficiency and so on.

9 So there are lots of issues that they could have
10 done a much more detailed review on, but the one that
11 they chose was by far the smallest, which -- I am not
12 suggesting that they did it on purpose particularly but
13 it just doesn't give a good impression that actually of
14 all these documents the group that was picked was the
15 one that was the smallest number and also for non-A,
16 non-B hepatitis I don't think that 1970 to 1985 is
17 probably the crucial time period to do it. If they were
18 going to do a really proper, thorough investigation of
19 that particular subject matter then you needed to
20 include after 1985 as well, which is when testing was
21 developed and it was identified and people were tested
22 for it and so on.

23 So that type -- if you were going to pick the
24 timeframe 1970 to 1985 then the obvious subject to look
25 at would probably be Aids rather than hepatitis. So

1 I think there are all sorts of questions as to why they
2 picked those documents to look at rather than any of the
3 other ones, given that they had previously said they
4 were going to review all of them, and then they only
5 reviewed a very, very small proportion. It just gives
6 the impression that they are not being as co-operative
7 and as helpful as they could be.

8 I did ask about releasing all of the rest of the
9 documents, in another effort where I request. They said
10 that they would release them in monthly batches but they
11 have not given -- I don't know if they have spoken to
12 you about this but when I have asked about whether or
13 not they are going to release them to the inquiry or
14 release them in time so that you have got use of them
15 before concluding, they will not commit to that at all
16 which again, doesn't seem very --

17 THE CHAIRMAN: We are not yet at the stage of asking for
18 specific documents. We are reading through the very
19 substantial number of documents we have had already.

20 A. I am sure you have an awful lot to read. But just in
21 terms of a commitment if they are going to release them
22 monthly I would be concerned if they started releasing
23 them in a timeframe where an awful lot of them were
24 going to be released well after a time that you actually
25 have enough space to be able to read them and look at

1 them before coming to a conclusion.

2 THE CHAIRMAN: As you know, it wouldn't be normal for
3 a department to release a document until they have
4 looked at it and if they say there are so many and we
5 can only do it a month at a time, one can appreciate the
6 difficulty, although it depends how many people you have
7 looking at them I suppose.

8 A. It does, and also clearly they have looked at them
9 already because actually they would not have been able
10 to categorise them according to subject and date period
11 unless they had actually gone through them already, so
12 there is obviously some work that has been done on all
13 of the documents. It is just that they are not
14 necessarily doing it as fast as they possibly could.

15 But I mean, I think just overall I have found it
16 quite illuminating. As a new MP I thought that --
17 I have been quite surprised at quite how reluctant they
18 are to provide information and quite how unhelpful they
19 have been. Some of their responses to my requests have
20 been extremely misleading or inaccurate or not providing
21 full information, and I think from some of the things
22 Lord Jenkin was saying earlier he has had the same --
23 they sort of answer one little part of it and by not
24 answering anything else you assume that there is nothing
25 else there, whereas actually there is an awful lot that

1 they are just not quite mentioning.

2 THE CHAIRMAN: Lord Morris has been working away at this for
3 some years.

4 A. Yes, I am sure. I think with a lot of people doing
5 digging and asking questions they still seem to be
6 extremely reluctant to provide the information that is
7 being asked for which gives a terrible impression,
8 I think, frankly to the people who were infected.

9 THE CHAIRMAN: Thank you very much. Obviously we will read
10 what you say as well but I think you have made it quite
11 clear what you regard as the important factors.

12 LORD TURNBERG: Just to check, from your research, have you
13 found out that when Elstree was regarded as being
14 somewhat deficient in some way or another did the BTS,
15 or whatever it was called in those days, seek funding
16 and was it resisted by the Department of Health or did
17 they not seek funding to upgrade? Where was the break
18 in preventing self-sufficiency to be developed?

19 A. I don't know that to be honest. I don't know it is only
20 in the last couple of days that I have learned about the
21 letters from the Blood Transfusion Centre directors to
22 the Department of Health, so this is sort of an
23 ongoing -- I still have a whole load of questions
24 outstanding from the department that I am waiting for
25 answers including some that for named days, so in theory

1 they should come back later this week. I believe it
2 when I see it, but that is still an area of work I am
3 working on. Others might be able to answer that.

4 THE CHAIRMAN: It seems when the adverse report was made in
5 1979 there was fairly quickly then a provision of
6 21 million to upgrade Elstree.

7 LORD TURNBERG: I really wanted to know whether that had
8 been something that the Transfusion Service had been
9 seeking for some time or whether it was when it was
10 found to be deficient that they suddenly decided.

11 A. I think they were aware much earlier on that there was
12 an issue with capacity at Elstree, were they not,
13 because --

14 LORD TURNBERG: Yes, we will no doubt --

15 A. In 75 David Owen gave an estimate of -- I can't remember
16 what the exact figures are, they are in there -- as to
17 how many units and how many blood donations were
18 required and they also knew the capacity of Elstree. So
19 if the money was not being put in earlier -- I think it
20 was only by 1978 that Elstree reached capacity anyway,
21 didn't it, so it was only three years later, so they
22 must have known there was going to be an issue.

23 The other thing is that if you look at the figures
24 for production in the UK and imports from the US it is
25 a very clear curve in that it hits a peak in 79 and then

1 absolutely tails off after that, whereas imports from
2 the US just go through the roof. So even if the
3 money --

4 LORD TURNBERG: That was because of the development of
5 science and the need for certain things.

6 A. Yes.

7 LORD TURNBERG: Can I ask you a separate question about the
8 committee on virological safety of blood where the
9 minutes seem to have gone from, I think it was 89 to 94
10 I think you said.

11 A. Yes. 13 of the files.

12 LORD TURNBERG: We will find out but do you know who the
13 chairman of the committee was at that time?

14 A. No, I can't tell you off the top of my head, sorry.

15 LORD TURNBERG: We will find out.

16 THE CHAIRMAN: I don't think we have been told.

17 LORD TURNBERG: No, we will find out.

18 MS WILLETTTS: Just briefly, given the extensive research and
19 investigations that you have conducted you clearly have
20 views on the scale of the tragedy, you have talked
21 a little about what has happened with people who were
22 infected by HIV. What is your view about the outcome or
23 any subsequent actions that should be taken?

24 A. Well, I think that -- I would hope that as an inquiry
25 panel you would have all of the information made

1 available to you that the department has. I think from
2 speaking to people who are affected by this that one of
3 the main things they want to know is actually what went
4 wrong, who knew what at what time and how certain things
5 were allowed to happen. I think without -- with
6 respect, I don't necessarily agree with Lord Jenkin that
7 people who were infected with HIV have had closure as
8 a result of the action in the 1990s because actually it
9 didn't go to court, none of the information came out and
10 still there is a huge amount of obfuscation about what
11 actually happened and who knew what when. And so
12 I think in terms of actually just literally knowing what
13 happened and understanding who knew what I think is
14 a really important thing.

15 I also do personally think that finance is a big
16 issue. A lot of people who are affected are living on
17 very low incomes. They were given pay outs in the early
18 1990s on the basis of life expectancy for HIV, people
19 who were HIV positive in the 1990s, which was very short
20 at that period of time, and the fact that people are
21 still living sort of 17 years later, living with the
22 disease I personally think we need to revisit that as
23 well. I mean, clearly I would have thought -- I don't
24 know whether that is in terms of your remit or not.

25 THE CHAIRMAN: Yes.

1 A. Yes, it is, because personally I think the levels of
2 poverty and the impact, the very severe impact that this
3 has had on people's lives, not just the immediate people
4 who were infected but their families as well has taken
5 a huge human toll and I think that needs to be
6 recognised as well and I don't think that was recognised
7 adequately in the early 1990s.

8 MS WILLETTTS: Thank you.

9 THE CHAIRMAN: Right, thank you very much, most grateful.
10 If anything arises at a later stage you have no
11 objection if we come back to you.

12 A. No, not at all. Thank you very much.

13 GRO-A (called)

14 THE CHAIRMAN: Good morning, Mr GRO-A, thank you very much
15 for coming.

16 A. Good morning, thanks.

17 THE CHAIRMAN: For reasons which are associated with the
18 hiccups that always happen on these occasions we have
19 only received a copy of your statement this morning.
20 How would you prefer to do it? Would you prefer to read
21 it out?

22 A. Could I read the statement if it is okay.

23 THE CHAIRMAN: Yes.

24 A. I would like to thank the inquiry panel for inviting me
25 to give evidence today. You will have heard from those

1 who were infected with imported factor VIII. I would
2 like to share with you now how I became infected with
3 HIV and Hepatitis C through contaminated BPL products
4 and the devastating effect it is having on my family and
5 I.

6 THE CHAIRMAN: I think you are probably the first witness we
7 have had who actually was infected through BPL products.
8 A. That's correct. I can trace it back as I tell you in
9 the statement.

10 THE CHAIRMAN: Yes.

11 A. Thanks very much.

12 My haemophilia is mild with no known relative with
13 the disease. I was diagnosed when I was 7 after having
14 my tonsils removed. So consequently I have had not had
15 so much treatment as a severe haemophiliac would have
16 had. Bleeding episodes were managed by the hospital
17 using cryo until 1982 when a delay in the treatment
18 given for a leg bleed would not heal so I was
19 transferred to Addenbrooke's hospital in Cambridge and
20 that is the main Haemophiliac centre for East Anglia.
21 It was there that I received my first ever batch of
22 factor VIII during my hospital stay which is how
23 I became infected with HIV and why I'm here today.

24 My life and that of my family was to change for ever
25 on a morning in September 1985 when I received a letter

1 from my local haemophilia unit telling me that I had
2 contacted HTLV 3 now known as HIV as a result of being
3 given contaminated factor VIII. I was numb with shock
4 but as my wife and I were unsure of what the
5 consequences were we asked for advice but were told
6 I looked okay so there was no need to worry. And at no
7 point were we offered any form of counselling. So we
8 were basically left on our own, a very bewildered
9 couple. My wife had to have a blood test to see if
10 I had infected her because it was known then that HIV
11 had been in blood products since around 1980, so for
12 three years I had been at risk of infecting my wife and
13 the wait for the results were unbearable thinking
14 I could have harmed the person I loved but thankfully
15 she was negative.

16 Over the next few months I became very frightened of
17 what would happen to me in the future. I had a wife and
18 three children to support. What would happen to them if
19 I were to succumb to HIV? What would happen if someone
20 found out that I had HIV? And my biggest fear of all
21 was what would happen to my children if their friends
22 found out.

23 I ran my own business at the time as a painter and
24 decorator and continued to work and try to put
25 everything to the back of my mind. In fact, in those

1 from my local haemophilia unit telling me that I had
2 contacted HTLV 3 now known as HIV as a result of being
3 given contaminated factor VIII. I was numb with shock
4 but as my wife and I were unsure of what the
5 consequences were we asked for advice but were told
6 I looked okay so there was no need to worry. And at no
7 point were we offered any form of counselling. So we
8 were basically left on our own, a very bewildered
9 couple. My wife had to have a blood test to see if
10 I had infected her because it was known then that HIV
11 had been in blood products since around 1980, so for
12 three years I had been at risk of infecting my wife and
13 the wait for the results were unbearable thinking
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15 she was negative.

16 Over the next few months I became very frightened of
17 what would happen to me in the future. I had a wife and
18 three children to support. What would happen to them if
19 I were to succumb to HIV? What would happen if someone
20 found out that I had HIV? And my biggest fear of all
21 was what would happen to my children if their friends
22 found out.

23 I ran my own business at the time as a painter and
24 decorator and continued to work and try to put
25 everything to the back of my mind. In fact, in those

1 early days I was so well I was almost in denial, even
2 though the media with its advertisements of fallen
3 gravestones and lilies done its best to remind me
4 otherwise.

5 Around 1989 my health started to fail. I started to
6 have recurrent chest infections but would go back to
7 work before I really had a chance to recover properly,
8 and being self-employed means no work, no wages. I had
9 a wife and three children to support so I had to return
10 to work before I was really fully fit. My health
11 continued to deteriorate by an alarming rate due to HIV.
12 I then contracted HIV related pneumonia which meant
13 I had a lengthy spell off work in which time my family
14 was hit badly financially. I was part of the
15 haemophilia litigation group at the time and at this
16 point my solicitor traced my treatments to
17 a batch that was known to be contaminated with HIV and
18 that batch came from BPL products. It was around this
19 time that the Government ex gratia offer was made and
20 I sought advice from my solicitor as to what I should
21 do. I was advised, as were probably all other infected
22 haemophiliacs, that we should accept the offer as
23 doctors at the time said in all probability we would be
24 dead or extremely ill within three years as the
25 prognosis at that time was poor.

1 Of course this news was devastating not just for me
2 but my wife as well and we had to keep some sort of
3 normality in our life for the sake of the children
4 although the ex gratia offer from the Government only
5 amounted to what at time was three years earnings from
6 me. I felt I had to accept as I didn't want my wife and
7 family to have nothing when I died as due to HIV I had
8 no life insurance or mortgage protection and the time
9 I had off work had drained us all of any savings we had.

10 My solicitor advised me to sign the waiver saying I
11 should say yes as I would probably be dead within
12 3 years and that was our last chance, and I feel we were
13 coerced into signing the waiver because if were to be
14 infected with any other viruses at a later stage we were
15 not able to take the Government to court, and if I
16 didn't sign I was told the whole litigation would fail,
17 which to me was emotional blackmail.

18 I then made a will and proceeded to put my affairs
19 in order to prepare for what I thought would be my last
20 couple of years. My health didn't really improve and
21 I was off sick more times than I was at work and whilst
22 in hospital I was being treated for one of the many of
23 the infections I was told by my doctor that I had to
24 give up work or I would be dead very soon as my body
25 couldn't cope with fighting HIV and working and I just

1 did not have the energy.

2 Although I was devastated at this news, I wasn't
3 totally shocked, but I felt cheated out of the living
4 I had. My decorating business was built from scratch
5 and I was employing two further directors such was the
6 work that was coming in. I felt castrated -- as the
7 breadwinner of the family I felt cheated out of earning
8 a crust from my family.

9 It was at this point I also became aware of my
10 Hepatitis C positive status. I wasn't actually given
11 the news. I saw my case notes whilst in hospital and on
12 the top was a lab report which had just come back and it
13 said Hepatitis C positive. Once again we had little
14 counselling and it was hard for the family to accept on
15 top of the HIV estoppel especially as I had contacted
16 this through NHS treatment.

17 THE CHAIRMAN: If I could just interrupt you. When you saw
18 this on a note it had been left on a table or something
19 had it?

20 A. Yes, my notes.

21 THE CHAIRMAN: Did you actually ask anyone about it?

22 A. Yes, the sister on the ward and she said she couldn't
23 comment, she would have to get my haematologist to talk
24 to me, which happened, and she came along and she
25 apologised for the way I found out.

1 THE CHAIRMAN: Confirmed it?

2 A. Yes, confirmed.

3 My wife and I decided to tell our daughters about my
4 illness and one of them was so traumatised and affected
5 by the news she got withdrawn and very depressed and
6 even tried to commit suicide as she was going through
7 a very hard time. We sought counselling for her and
8 after a while her psychological well being improved and
9 after going through the usual teenage problems she has
10 turned out to be a wonderful daughter with her life now
11 well and truly back on the rails for which I am
12 thankful.

13 My wife and I had to keep a normal front to the
14 people who knew us and basically we lived a lie as
15 people were inquisitive as to why I was not working. At
16 one stage the rumour was that I was a drug runner, which
17 may sound funny now but it was my daughter who told me
18 this as she found out at school what people were saying
19 about me and I felt terrible for her as she had to
20 endure a lot of the gossip.

21 I was frightened that me having HIV would come out
22 as quite a few people knew I had haemophilia and as
23 there has been a lot of media coverage at the time about
24 haemophiliacs becoming infected I thought it would only
25 be a matter of time before people put two and two turn

1 together. I was not so much frightened for myself but
2 for my children and to what they would have to endure.
3 Because I didn't have any visible means of income as
4 I said the gossips in the close were working in
5 overdrive. I had new windows installed and then got
6 a new car on the motorbility scheme which I had for a
7 matter of days before it was vandalised. I got it
8 repaired and it was vandalised again.

9 THE CHAIRMAN: Did you ever discover --

10 A. Who done it?

11 THE CHAIRMAN: First of all, who did it, yes.

12 A. No, the police actually took it so seriously they set up
13 a video camera in the front of the house and nothing
14 ever came to light. Unfortunately it wasn't done again
15 so we never got to bottom of -- I had my suspicions
16 obviously but it was, you know.

17 THE CHAIRMAN: I was wondering what was their motive? What
18 was behind it? Was it because they thought you had
19 Aids?

20 A. That is the problem you see. I don't know whether it
21 was that or whether it was the fact because I wasn't
22 working, because you turn up in a new car, because you
23 go on holiday, because you get new windows people get
24 jealous. It could have been because of Aids. I just
25 don't know. Unfortunately it's not something you go

1 from door to door and sort of ask, and so it was
2 a horrible time obviously.

3 THE CHAIRMAN: Sure.

4 A. After this the family needed a holiday but when we came
5 home some kind person had thrown hot fat over our new
6 windows. I have no idea if the person or persons
7 responsible knew I had HIV or were jealous of the fact
8 that we had new windows and a car. I was blowing up
9 with temper and anger at the situation and I was leaving
10 my family very concerned for my emotional well being.

11 I then became so depressed with the situation I had
12 a nervous breakdown and I was admitted to a psychiatric
13 hospital for three weeks. I knew then that we had to
14 move for the sake of my sanity and more frightening the
15 safety of my family.

16 We then decided to move. I thought I was dealing
17 with things okay and then two close friends with HIV
18 died. I was angry. I was devastated. I became
19 impossible to live with and I had frequent mood swings.
20 My wife and I had constant arguments due to the pressure
21 we were under. I would be ill one week, fine the next
22 and the side effects of the drugs for HIV were making me
23 ill. And I was turning against the very person who
24 wanted to help me, which was my wife.

25 We decided to tell our son who, like his sister,

1 took the news badly. I became so unbearable to live
2 with something had to give and that was my marriage.
3 I felt it would be better for the family if I moved out.
4 I know I wasn't a nice person to live with. Doctor
5 Jekyll and Mr Hyde comes to mind. Me moving out had
6 a deep effect on my son. He started to get in trouble
7 at school and I had to live on my own for the sake of
8 everyone.

9 During this time my salvage drug combination failed
10 and I became very ill and I was told that I was in the
11 last chance saloon regarding my drugs treatment.
12 Fortunately I responded and I am still on the same
13 tablets but still suffering the nasty side effects but
14 still here.

15 After coming out of hospital feeling I had another
16 chance of life I was determined to get counselling and
17 try and help myself. This I did with the help of my HIV
18 nurse and family and I am pleased to say the counselling
19 worked. After four years of living on my own I am
20 pleased to say I am now back in the family home.

21 We have rediscovered our love but what we don't have
22 is financial security which is due to my illness and
23 I still feel cheated out of a life that would have meant
24 I could have provided for my family and also would have
25 had the money to help my children get married and money

1 at 49 just to enjoy life. But instead I am trapped in
2 a poverty trap through no fault of my own. I live off
3 benefits and what little the Macfarlane Trust can
4 provide, and to rub salt in the wound I have just
5 finished the other day filling out yet another form for
6 social security that tells me because my son who is
7 working and living with me and my wife we must use his
8 earnings to support me. So now my dignity is totally
9 destroyed.

10 At the beginning of my statement I touched on the
11 fact that I was given contaminated British factor VIII
12 and I think it is making that point as a lot of media
13 attention has been on the fact that a lot of
14 haemophiliacs were infected with American factor VIII.
15 I and other haemophiliacs were not and because of
16 Government incompetence at the time BPL health products
17 were allowed to infect me and a lot of other
18 haemophiliacs.

19 In my mind it matters little where the factor was
20 sourced as over 4,000 haemophiliacs have been infected
21 with HIV and hepatitis and heaven knows what other
22 virus. What does matter is that each and every one of
23 us was infected with what we thought was safe treatment
24 from the British NHS which we now find was very unsafe
25 treatment.

1 Thank you for listening.

2 THE CHAIRMAN: Thank you very much for being so frank with
3 us.

4 LORD TURNBERG: Thank you very much, a very touching and
5 moving story. It is good to see you here today.

6 A. Thank you.

7 LORD TURNBERG: How are you feeling now?

8 A. As I say, I responded well to the drugs. The side
9 effects are the problem sometimes you have with the
10 drugs, not just sickness, nausea that sort of thing but
11 some will give you high cholesterol so you are at risk
12 of heart attacks things like that. It is just getting
13 through day to day life really.

14 LORD TURNBERG: Has the Hepatitis C affected you.

15 A. The only way it's affected me is I had to go to
16 hospital, I had a liver biopsy. I had a slight bit of
17 scarring but I was fine. That side of it has been okay.
18 It is the HIV side of it that I must admit ...

19 LORD TURNBERG: It was in 1983 that you --

20 A. 82 that I was infected, yes.

21 LORD TURNBERG: -- that you got the --

22 A. December 82.

23 LORD TURNBERG: As a result of that, have they looked back
24 and traced the individual from whom that came?

25 A. No, that was something that the solicitor at the time

1 when we had the litigation in the 90s tried to do. They
2 traced back the batch but because I was told there was
3 a problem with Elstree, with the administration it was
4 very difficult to get.

5 LORD TURNBERG: They know the batch?

6 A. They know the batch number, yes, and they know it is
7 BPL.

8 LORD TURNBERG: Have you had any blood products or
9 transfusion since that time?

10 A. Yes, I have had. I have had cryo since. I have had
11 factor VIII since. I have had American factor VIII
12 since but that was after 85. Obviously being mild
13 I don't have so much as a severe haemophiliac.

14 LORD TURNBERG: Do you have any idea how many patients were
15 infected from British?

16 A. A rough estimate -- this is only what I was told -- it
17 was around about 3 to 400 but that was with HIV, but
18 Hepatitis C would have been far more. I haven't got the
19 figures for that.

20 LORD TURNBERG: Were you of the impression that in 82 that
21 they should have been testing for HIV all the donors for
22 the factor VIII?

23 A. In 1982 was I aware?

24 LORD TURNBERG: In 1982 when you were infected?

25 A. No, I wasn't aware of anything really.

1 LORD TURNBERG: Do you think they were aware, the
2 transfusion people?
3 A. At the time I just I would have said no, but having
4 found out what I have found out, seen the documents
5 I think, yes, I think they probably knew there was
6 a risk. Just since actually coincidence, I have spoken
-7 to one or two other mild haemophiliacs and they got
8 treatment either in 82 or 83 with factor VIII for the
9 first time some of them. It just seems a big
10 coincidence to me. Obviously that is for the inquiry to
11 comment.
12 LORD TURNBERG: There weren't many patients in the UK who
13 had HIV in those days.
14 A. No, obviously it wasn't diagnosed until 85 myself you
15 see. But my personal opinion is, yes, you know.
16 LORD TURNBERG: Thank you.
17 MS WILLETTTS: GRO-A may I just ask you two things. When you
18 saw your notes saying that you also had Hepatitis C,
19 when was that?
20 A. That would have been, I think it was 1994.
21 MS WILLETTTS: Did it say when you had become infected?
22 A. No, all it was was a lab report literally on the top,
23 what you get back from the blood test, just said
24 "Hepatitis C positive" and when I had a word with my
25 doctor she didn't know exactly when I was infected.

1 That is what she told me. She said it could have been
2 the same batch but on the other hand because I have had
3 other treatment in the meantime she couldn't pinpoint
4 the time.

5 THE CHAIRMAN: How did they manage to pinpoint it later when
6 the solicitor enquired?

7 A. What the hepatitis? They never pinpointed the hepatitis
8 to when that was ever given to me. The HIV they did but
9 not the hepatitis.

10 MS WILLETTTS: Did you ask whether at any point they might
11 have chosen to tell you?

12 A. Yes, I was quite angry at the time. In fact, me and my
13 wife went to see haematologist and we were extremely
14 angry because that is not the first time we were treated
15 for, in fact, I got treated so poorly by a
16 hospital that I eventually went down to Chelsea and
17 Westminster which is where I go now at which I get far
18 better standard of care. Yes, very angry. But having
19 seen a lot of people's testimonies, and I wasn't the
20 only one. It seemed to be endemic at the time.

21 THE CHAIRMAN: When did the hospital know that you had HIV
22 and when did you know?

23 A. The hospital people knew -- well they told me -- I went
24 for a test in the summer of 85 and I was told by letter,
25 bearing in mind it was a letter, that I had HIV

1 in September, early September.

2 LORD TURNBERG: So within a month or two that they knew that

3 you knew?

4 A. Yes.

5 LORD TURNBERG: Even though they informed you in a rather

6 callous way.

7 A. The funny thing is they told everyone in the family not

8 to worry because I had mostly cryo before. I had only

9 had a few batches in Addenbrooke's hospital and

10 everybody was told not to worry. But even after we

11 found out, honestly the haematologist said, well he

12 looks well so don't worry.

13 MS WILLETTTS: Were you given any advice when you were

14 informed about your HIV status of the need to protect

15 your family or anything else?

16 A. Not much advice. They said we've heard this can be

17 sexually transmitted so just be a bit careful and that

18 was all, honestly. It was -- honestly it was so poor.

19 It was -- in fact we had to -- we weren't very pleased

20 initially with the hospital so we went to

21 Cambridge to see the haematologist there. But she

22 actually had a go at us for going to Cambridge and not

23 taking what the previous haematologist said. She made my

24 wife cry.

25 MS WILLETTTS: May I ask one question about the waiver. Can

1 you just tell me, [GRO-A], what exactly were you told would
2 happen if you didn't sign the waiver? Can you remember
3 exactly what that was?

4 A. At the time the solicitor said, this is a class action,
5 this is not an individual -- even though I was getting
6 legal aid at the time. He said if I was to turn down
7 this offer he said in all probability the legal aid
8 would be withdrawn and he said if you can afford to fund
9 this on your own fine but my advice to you is to go
10 along, bearing in mind how long you have to live which
11 is what I was basing on at the time. I wasn't very
12 happy signing the waiver but I thought well I just hoped
13 there would be no other diseases in the pipeline to be
14 honest.

15 THE CHAIRMAN: But you were told that the whole settlement
16 would collapse if you refused it?

17 A. Yes, if any of us pulled out then the Government said --
18 well this is what I was told, that the whole settlement
19 would collapse.

20 MS WILLETTTS: That is what I was getting at.

21 A. So in a sense it was coerced and it was emotional
22 blackmail really to be honest. That is how I feel.

23 MS WILLETTTS: Thank you.

24 THE CHAIRMAN: Thank you very much, Mr [GRO-A].

25 A. Thank you, now I have my daughter sitting here. This is

1 [GRO-A], the daughter I was speaking about in my
2 statement.

3 THE CHAIRMAN: Indeed.

4 A. Also my other daughter has prepared a small statement,
5 but it is very emotional for me to read it out, so after
6 [GRO-A] has spoken is it all right if my friend
7 [GRO-A] reads out the statement on behalf of my
8 other daughter.

9 THE CHAIRMAN: We are quite happy for that to happen.

10 A. Will it be okay?

11 THE CHAIRMAN: But if you like you can just hand it up to
12 us. We would certainly read it.

13 A. If it could be read out loud because she would
14 appreciate that because she feels her voice -- she would
15 love to be her today but she wanted to know how it has
16 affected the family. Is that okay?

17 THE CHAIRMAN: Yes, indeed. Thank you very much.

18 [GRO-A] (called)

19 THE CHAIRMAN: I don't think we actually have your name.

20 A. It is [GRO-A].

21 THE CHAIRMAN: Yes.

22 A. I was 11 years old when I was first told that my father,
23 [GRO-A], was HIV positive. Needless to say I was
24 devastated. All I could think about was why does this
25 have to happen to my Dad, my Dad was one of the good

1 guys.

2 I can't read, I am sorry.

3 THE CHAIRMAN: Would you prefer it if someone read your
4 statement?

5 A. My name is GRO-A and I am going to read this on
6 behalf of GRO-A:

7 "I was 11 years old when I was first told that my
8 father, GRO-A, was HIV positive. Needless to say
9 I was devastated. All I could think about was why does
10 this have to happen to my Dad, my Dad was one and still
11 is one of the good guys. I was so hurt and angry. All
12 I could think of was 'My Dad is going to die'. I found
13 this very difficult to deal with and at 13 was referred
14 to a counsellor but unfortunately she did not understand
15 the illness and this became a waste of time.

16 Due to the stigma of the illness I was not allowed
17 to tell anyone about my Dad and this was also difficult.
18 People used to make AIDS jokes and I would just stand
19 there in silence. By my teens my Dad wasn't working any
20 more and a lot of people at school knew this. People
21 used to say that my Dad was a drug dealer and that's how
22 we got money. I can laugh now but then it really hurt.
23 Because my Dad wasn't able to work any more my brother,
24 sister and I used to get free school meals. I never
25 used to claim mine because if I did then people would

1 ask questions and I hated that because I would have to
2 lie about what was really wrong with my Dad as if he had
3 an embarrassing illness or done something wrong. So I
4 just wouldn't eat. It was easier that way.

5 When I was 15 my Dad had a nervous breakdown and was
6 sent to a psychiatric hospital. I can remember he came
7 out on day release from the hospital and his hands were
8 shaking, he was really quiet, he wasn't himself at all.
9 It was so difficult to see my Dad fall apart like that.

10 ~~At 18 years old I was put on anti-depressants,~~ I got
11 signed off work for having depression for almost a year
12 and I was referred to a different counsellor but again I
13 couldn't talk to her because she didn't understand the
14 illness. ~~During this time my parents' marriage was~~
15 ~~breaking up. It was then that it all became too much~~
16 ~~for me and I took an overdose and tried to commit~~
17 ~~suicide.~~ This wasn't the first time I had taken an
18 overdose but this time I had taken so many pills that
19 I was hospitalised. I just couldn't cope with it all
20 any more and just wanted it all to end. ~~When I went to~~
21 ~~see the hospital psychiatrist to see if I could go home~~
22 ~~she said to me 'At least your Dad isn't paralysed'.~~
23 ~~I couldn't believe it. My Dad was dying through no~~
24 ~~fault of his own and she was comparing the illness to~~
25 ~~being paralysed.~~ How could people think like that?

1 ~~People just do not understand this illness and still the~~
2 ~~stigma towards it continues.~~

3 ~~Two weeks later my parents separated. I can~~
4 ~~remember my Dad crying to me about everything. I had~~
5 ~~never seen a man cry before, let alone my Dad. My~~
6 ~~parents didn't speak for a while and times were tough.~~
7 ~~There was talk of a divorce and I even stopped speaking~~
8 ~~to my Mum for a while because I blamed her for it all.~~
9 ~~My whole life was in ruins.~~

10 I was sent to see another counsellor and this time
11 she did help me. She understood because she had
12 a friend die of AIDS a few years before. It was really
13 nice talking to someone that understood. ~~During this~~
14 ~~time my Dad became really ill. He had been ill quite~~
15 ~~a few times before and has always been in and out of~~
16 ~~hospital. But he has never been like this. He did not~~
17 ~~have a carer any more as my Mum did not live with him so~~
18 ~~I took over this role. This was incredibly difficult~~
19 ~~seeing him in so much pain. Every time my Dad gets ill~~
20 ~~I always wonder, 'Is this it?' This illness is so~~
21 ~~unpredictable, you never know when it will happen, and~~
22 ~~I've seen so many of my Dad's friends die of the same~~
23 ~~thing.~~ My Dad became so ill that he was hospitalised
24 and no one was able to see him. This was really hard.
25 It scares me every time he's ill and it's horrible to

1 see him that way knowing that there is nothing you can
2 do to help.

3 Since then I have moved out of my parents' house.
4 I turned to drugs for a while, got myself into debt and
5 began self-harming. It was only when I met my current
6 partner two years ago that I have finally been able to
7 start settling down. I am now 25 years old but I have
8 never come to terms with or accepted what has happened
9 to my Dad and it has never got any easier.

10 My parents are back together now and my Dad moved
11 back in with Mum a few years ago. My Dad now has fully
12 blown AIDS and also has Hepatitis C, both given to him
13 through contaminated blood products. I hate what has
14 happened to my Dad and not a day goes past when I don't
15 think about it. ~~I think people have not thought about~~
16 ~~the effects that this has had on the dependents.~~ This
17 has been difficult for me but I can't imagine what my
18 Dad must be going through. My Dad had to give up a good
19 job and has had to struggle financially since I can
20 remember. He has never even had so much as an apology
21 for what has happened to him. No one deserves this. ~~My~~
22 ~~parents are my heroes. They have both had to deal with~~
23 ~~so much in their lives and have never given up hope that~~
24 ~~one day my Dad will get the justice that he deserves"~~
25 THE CHAIRMAN: Thank you.

1 A. I have also been asked to read [GRO-A] statement. Is
2 that okay?

3 THE CHAIRMAN: Yes, please.

4 A. Okay:

5 "My name is [GRO-A]. I am 27 years old and
6 found out my Dad was HIV positive when I was 11.
7 16 years have passed and I still haven't fully come to
8 terms with this travesty. How can an 11-year-old girl
9 understand the complex illness which has infected her
10 Dad? I remember crying myself to sleep on many

11 occasions thinking I'd wake up and my Dad would be dead.

12 I couldn't tell a soul at school as the gravestone ads
13 were on the TV and that's what everybody spoke of.
14 I made the mistake of telling one friend and soon enough
15 everybody thought my Dad was a druggie, my Dad was the
16 person that stuck dirty needles in himself. I was
17 ostracised for quite some time. Having a boyfriend was
18 extremely difficult. I would have to decide if I should
19 tell them the truth and risk them running a mile or lie
20 to them. Not everybody understands this illness even
21 now.

22 My Dad had a thriving business which he had to give
23 up because of his illness. This affected all of us as
24 he became a shadow of his former self and we ended up
25 literally walking on eggshells around him as we didn't

1 ~~know when he would explode next.~~ All this pressure
2 finally mounted up and he was admitted to a psychiatric
3 hospital after having a nervous breakdown.

4 I didn't know my Dad at this point. He wouldn't
5 look at us, he wouldn't speak to us, nothing. This tore
6 me apart inside. I thought I had truly lost my Dad for
7 good. It took a very long time but my old Dad came
8 back. Shortly after this I was faced with nearly losing
9 my sister. She tried to commit suicide. Fortunately
10 for all of us she was unsuccessful. It had been too
11 much for her to cope.

12 A few years passed and my world fell apart again
13 when I was told that my parents were separating. The
14 strain of Dad not working and Mum being restricted due
15 to so much red tape within the benefits trap, et cetera,
16 along with the obvious health problems, had finally made
17 them snap. I always had such a strong family and this
18 was so out of the blue. Everyone argued constantly.
19 Nobody was civil with anyone in the family any more. We
20 were on a slippery slope. My Dad eventually moved out
21 and I had to share my time between two parents.
22 I sometimes felt like the parent having to referee what
23 seemed like petty squabbles.

24 After three years of going through hell they managed
25 to patch things up and move back with one another.

1 I now have a 17-month-old daughter. The decisions I had
2 to face along with my fiancée during my pregnancy could
3 and should have been avoidable. We had to decide
4 whether or not to have our embryo screened for
5 haemophilia and what to do if it was a haemophiliac.
6 Abort? Who is to say that in 20 years' time there is
7 not a similar disease out there threatening the
8 haemophilia community just as AIDS has? The Government
9 screens blood now for things they know but nobody knows
10 what may happen in the future.

11 We eventually decided not to have any testing done
12 and let nature take its course. But we shouldn't have
13 to play with nature, we shouldn't have to think so
14 cautiously about our health. But I truly do not trust
15 the Government or the health service after what they
16 have done to keep us safe.

17 My Dad is well at present but I haven't mentioned
18 the numerous times he has been in and out of hospital
19 for one thing or another. We have been told a few times
20 that if this particular combination therapy, the drugs
21 he takes, doesn't work, then there is really nothing
22 else left.

23 In my mind I have said goodbye too many times. ~~This~~
24 ~~awful ordeal has affected all the children of all these~~
25 ~~men. It is about time we were given an apology too.~~

1 GRO-A."

2 THE CHAIRMAN: Thank you very much. That has conveyed
3 a picture to us which no amount of reading could have
4 done. Could we have GRO-A statement, please. We have
5 copies of the others.

6 MR MEHAN: It has been sent to us, GRO-A, thank you.

7 THE CHAIRMAN: Thank you very much, Mr GRO-A.

8 ~~THE REVEREND PREBENDARY ALAN TANNER~~ (called)

9 THE CHAIRMAN: Good morning.

10 A. Good morning.

11 THE CHAIRMAN: Mr Tanner, I do not know whether you were in
12 when I said there was a hiccup in the communications.
13 We only received your statement this morning. I do not
14 know how you would prefer to do this. Would you like
15 either to make a statement of your own or to read your
16 statement out?

17 A. It is a very brief statement. I thought I would err on
18 the side of brevity because, as I said in the statement,
19 I am very much aware that as I come to -- come before
20 you now, many have been before me and have no doubt
21 touched on the major points, the history, the whole
22 genesis and evolution of it. So I made just a very
23 brief personal statement and with the thought that
24 perhaps you would put questions to me on matters which
25 had not really been covered.

1 THE CHAIRMAN: Yes, thank you.

2 A. Although I must say in the light of the kind of
3 testimony that has just been given to us, which are
4 very, very moving and can be repeated many, many times
5 by members of the haemophilia community, it is almost
6 a switch in mood if I come before you talking about the
7 kind of genesis of Macfarlane Trust compensation and the
8 like. We could almost do with a pause to reflect on
9 what has been told us so -- what I say I would not wish
10 in any way to detract from the force of the
11 testimonies --

12 THE CHAIRMAN: I follow that but --

13 A. -- which have come before us.

14 THE CHAIRMAN: -- unfortunately perhaps --

15 A. This is the way it has turned out.

16 THE CHAIRMAN: -- we have to take as much evidence as we can
17 in one session.

18 A. I understand that. Shall I read my brief statement?

19 THE CHAIRMAN: Yes, if you can do that.

20 MR MEHAN: Can I ask you also to go through your history of
21 involvement in the top box.

22 A. I was chairman of the Haemophilia Society from 1975 to
23 1997. I was chairman of the Macfarlane Trust from its
24 inception until the year 2000 and of the Eileen Trust
25 associated with it. I was chairman of the World

1 Federation of Haemophilia from 1971 to 1996. I have
2 trouble reading this. It is such small print. Excuse
3 me. I must get my reading aid out. You will forgive me
4 for this. I was chairman of the World Federation from
5 1971 to 1996.

6 THE CHAIRMAN: If I could just interrupt you there. This is
7 the first time I think that we have heard of the World
8 Federation. Can you tell us just a little about it.

9 A. It was formed in 1963 and it was then the coming
10 together of six national societies because there were
11 only six at the time. Six national societies who came
12 together just to share common concerns particularly
13 about the availability or the lack of availability of
14 treatments. And on the international field it was to
15 try and share what -- such experience as there was of
16 haemophilia treatment and care.

17 That was very, very much in the early days before
18 there was any thought of haemophilia centres and the
19 like. And indeed, in 1963 very few haematologists were
20 specialising in haemophilia. So it was a coming
21 together just of lay people, but quite soon after that,
22 still in the 1960s, we were very well supported by
23 medical advisers who were haematologists with a special
24 interest in haemophilia.

25 And it was then we pretty soon developed a kind of

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3 me. I must get my reading aid out. You will forgive me
4 for this. I was chairman of the World Federation from
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20 specialising in haemophilia. So it was a coming
21 together just of lay people, but quite soon after that,
22 still in the 1960s, we were very well supported by
23 medical advisers who were haematologists with a special
24 interest in haemophilia.

25 And it was then we pretty soon developed a kind of

1 altruistic mood in being very concerned about developing
2 countries, because those six, as you might imagine, were
3 from those that were rather advanced, if you can say
4 that, in haemophilia care, European countries, United
5 States, Canada, Australia, most of those as it happens
6 who had blood transfusion facilities.

7 But we developed that concern for the developing
8 world, and so we have now got to the state where there
9 are very, very more member countries and it is quite
10 a powerful organisation, not only in sharing information
11 internationally but in making relationships with World
12 Health Organisation and the like and in rationalising
13 the treatment and the care and the provision of
14 facilities, not least in the research looking for the
15 cure.

16 So that is -- it is quite an important point.

17 THE CHAIRMAN: Yes, it is important.

18 A. And you note as well, it is not a slip of the
19 typewriter, it is the hemophilia with the American
20 spelling, stet, as they say.

21 Shall I turn to the statement?

22 THE CHAIRMAN: Yes, please.

23 A.

24 GRO-A
25

1

2

3

4

5

GRO-A

6

GRO-A

Here

7

I repeat things which you have already heard. In 1955

8

there was no specific treatment for bleeding episodes,

9

except as you will know by now blood transfusion and the

10

like. Bed rest was mostly the recommendation from the

11

haematologists. Cold compresses on swollen joints, and

12

everybody here with haemophilia will know all about

13

that. And then there is a very interesting little

14

element here. Russel's Viper Venom was carried in the

15

pocket of people with haemophilia in those days as

16

a coagulant for excessive external bleeding, but that

17

was about the measure of it; never move without your

18

Russel's Viper Venom.

19

So then I am very anxious to communicate to you the

20

kind of the mood of people with haemophilia in those

21

days because it was -- the future was blank. Life

22

expectation was very, very limited there in 1955. So,

23

as I say in my statement, we were greatly comforted by

24

the discovery of Cryoprecipitate Professor Judith Pool

25

in the United States, who I knew personally through the

1 World Federation, because I travelled with her, and that
2 really was an enormous breakthrough.

3 It meant that for the first time they could isolate
4 factor VIII and inject it almost immediately following
5 a bleeding episode. It was a very clumsy procedure, as
6 you have probably gathered by now, in these kind of
7 plasma bags, and the nurses had to exercise great
8 patience in extracting it by syringe. They took ages to
9 do it but it was all worthwhile because there it could
10 be injected immediately in the hospital, immediately
11 there was a bleeding episode.

12 The complications were, in the very nature of the
13 case being Cryoprecipitate, it had to be kept at very,
14 very low temperatures, so you needed facilities to be
15 able to deal with that.

16 In the next step, as I say in my statement -- I will
17 not read it word for word -- but the next step, and it
18 really was miraculous, when we came across factor VIII
19 concentrate, because that did away with the clumsiness
20 of extracting it all from the Cryoprecipitat bags. It
21 was just, as you will know by now, the materials
22 would -- just put in solution into a syringe.

23 The important thing is that the boys and men were
24 taught how to administer this by themselves
25 intravenously, and all the doctors would know that was

1 a tremendous breakthrough, because at the time, looking
2 back on it in that historical context, they even said it
3 was illegal for a nurse to do that, to inject it
4 intravenously, on the principle that you can take things
5 out of the veins but you couldn't put them in.

6 So the doctors at that time, the haematologists,
7 made a great leap of faith in doing that contrary, as it
8 were, to the legal position until it was properly
9 established.

10 THE CHAIRMAN: But previously you had had to drag yourself
11 to hospital, probably a long wait in hospital.

12 A. Absolutely.

13 THE CHAIRMAN: And so forth.

14 A. Here I just want to pay tribute to many of the doctors
15 that I know. Remember they were haematologists. By and
16 large they were academics. And it is to their credit
17 that many of them developed this kind of very, very
18 personal relationship with their patients. In spite of
19 what we have heard, and I detract in no way at all from
20 all the testimonies that we have heard, and there are
21 many, many more to come, of these very distressing
22 situations, in these days in the 1950s and 1960s there
23 was a very special relationship between the doctors and
24 their patients. They mostly knew their families because
25 it was a very rarified disorder, there weren't many of

1 them about.

2 What there were was a very close relationship
3 between doctor and patients, [GRO-A]
4 [GRO-A]
5 [GRO-A]
6 [GRO-A] And I think it is -- it
7 should not go unnoticed, in spite of what we are hearing
8 about in the developing years, it should not go
9 unnoticed the degree of dedication of those particular
10 doctors who after all were in a pioneer situation. It
11 was all a mystery in those days.

12 But I will testify again to the transformation which
13 took place once the boys and men were taught how to
14 infuse themselves, which is not a very simple thing
15 unless you are taught how to do it. They were taught
16 how to infuse themselves. They took their factor VIII
17 home, had a little fridge to put it in. Everybody here
18 will know all about this. They were able to treat
19 themselves immediately and the world opened up because
20 no longer need they have the kind of swollen joints
21 which were the feature of all people haemophilia [GRO-A]
22 [GRO-A] no longer did they need that because, as every
23 person with haemophilia will know, they can anticipate
24 their bleeds.

25 And this again is a very important element in it

1 all. It is why doctors in those days in the 1950s and
2 1960s took the patients very much into their confidence
3 and why there was such a close rapport between patient
4 and doctor. Because the doctors knew that no one knew
5 more about haemophilia than the person with haemophilia
6 himself, and they often used to say, and I have heard
7 them say, to the boy, "Do you think it is a bleed?"
8 Doctors do not very often do that. They knew more about
9 haemophilia than many of the doctors who were treating
10 them.

11 And that opened up a new world to them and we had
12 people -- when we had congresses for the World
13 Federation of Haemophilia we had boys and men travelling
14 with us. That would have been unthinkable in days gone
15 by. They carried with them their little phials of
16 factor VIII and their little kits, and wherever they
17 were in the world, in Brazil, in Japan, whatever, they
18 were able to look after themselves. The important thing
19 is they were being weaned from their centre and this was
20 this new life of independence.

21 THE CHAIRMAN: Would you answer one question which is in my
22 mind: was there a change among haematologists? Because
23 at a later stage we have had a rather different picture
24 of them. Fairly clearly -- you say they were academics,
25 it is not surprising that they wanted to do research,

1 but they did not seem to have taken patients into their
2 confidence about the research they were doing. Did you
3 detect any change of that kind?

4 A. No, I must say I didn't see that. I know they were --
5 because they were academics, research was part of their
6 life-style, wasn't it, really. Whether it was
7 technically research or whether it was observation is
8 another matter. Research -- I was a physicist myself
9 and to me research means a clearly defined protocol.

10 THE CHAIRMAN: Yes, they obviously wanted to learn more
11 about the disease and the effective treatments.

12 A. Absolutely, as did we all. So did the boys with
13 haemophilia wanted to know more about it, and in my
14 experience if they asked questions they were given an
15 answer. But gradually -- I mean you have touched on
16 a very important point really because as time went on
17 haemophilia became a speciality, whereas before it was
18 part of general haematology, people began to be
19 interested in haemophilia and the other side of the
20 coin, thrombosis, so you find some of the centres were
21 haemophilia and thrombosis centres.

22 ~~I just wanted to paint that kind of general~~
23 ~~background of almost euphoria that was about when these~~
24 ~~treatments came in. That was why it was even more~~
25 ~~devastating when the blow struck and HIV came into the~~

1 their lives. I say [GRO-A]
2 [GRO-A] as you hear, of these cases
3 which are being presented to us with the unbelievably
4 distressing situations, and I just mentioned -- just as
5 a personal note in my own case I --

6 THE CHAIRMAN: Just before you go on, I wonder whether you
7 could help me with something that has been in my mind
8 for some time. The department has said in their latest
9 report on documents that I think in 1975 or thereabouts
10 when the question of self-sufficiency first arose the
11 society actually asked the Government not to prevent the
12 import of American products, presumably because
13 otherwise there might not have been enough products of
14 any kind. Can you shed any light on that?

15 A. No, I have never heard that before. In fact I was
16 associated with the World Federation of Haemophilia at
17 the time and again, I mention in the statement, we were
18 very very concerned in the World Federation of
19 Haemophilia and it was a great debate which went on but
20 the outcome of that was it was adopted as the policy of
21 the World Federation that all countries should be
22 self-supporting.

23 THE CHAIRMAN: I think they were saying that, yes, but they
24 were suggesting that until this country became
25 self-sufficient they didn't want American products to be

1 picture. Again, tracing it historically, it didn't come
2 abruptly, as some might have imagined. It came in
3 a really mysterious way without anybody knowing anything
4 about what was happening. There were rumours about
5 things happening in America. There was an article in
6 a New England journal of medicine which touched on some
7 strange things happening through the blood transfusions
8 and so on.

9 And I remember -- and I have a note here -- and we
10 were so concerned about it as a society in 1983 we gave
11 over the annual general meeting to a discussion of this
12 mysterious element which had come into our lives, and
13 there we assembled quite an important group there, again
14 Professor Arthur Bloom from Cardiff and Dr Forbes from
15 Scotland and others who came to help us think through
16 this.

17 They were as mystified as we were but the general
18 outcome of that was that as we knew so little about it
19 and it hadn't yet at that stage turned out to be the
20 threat which we now know it to have been, the advantages
21 of carrying on with treatment far outweighed any kind
22 of -- any kind of threat that there might have been, any
23 kind of malrecommendations on it. And that was the mood
24 there in 1983.

25 LORD TURNBERG: It sounds as if everyone was swept up in

1 a great wave of enthusiasm in the 1960s, 1970s and
2 perhaps even to the 1980s, and there was a slow
3 realisation that all was not right beginning in the
4 1980s and it sort of crept in. Is that the general
5 feeling?

6 A. That is more or less, and it was devastating, and I am
7 speaking for some of the doctors who are not able to
8 speak for themselves. Unfortunately as we have an
9 inquiry like this many of the doctors concerned who
10 would have been testifying have gone before us. Many of
11 those like Professor Roger Hardisty -- well, Macfarlane,
12 RG Macfarlane, after whom the Macfarlane Trust was
13 named, they were pioneers in haemophilia but they are no
14 longer able now to speak to us about it from St Thomas's
15 and the like.

16 LORD TURNBERG: So when we talk about they were doing
17 research of course they were trying to find new
18 treatments, were they not?

19 A. They were indeed, and trying to find the best kind of
20 dosages, and all that came into it, but I say again,
21 they were not academics in the kind of Oxford don cold,
22 clinical style. They were academics who had this
23 special rapport. I am thinking of them individually
24 now. The people that -- that concerned me, they really
25 had a close relationship with their patients and no one

1 was more devastated than they when everything went
2 wrong. I want to put that on the record too.

3 LORD TURNBERG: Did you have medical advisers in the
4 Haemophilia Society?

5 A. We did indeed, and they were these that I am mentioning
6 now of the highest possible calibre and recognised as
7 being such internationally and they were in the
8 forefront of all research that was going on and no one
9 was more shattered than they when this turned out to be
10 the case.

11 You see in places like -- without going into too
12 great detail, somewhere like the Newcastle centre, they
13 were in the forefront of adopting as we now say
14 comprehensive care. Once we got into this method of
15 treatment -- I don't know whether you have heard the
16 term before -- they treated not just the haemophilia
17 blood components, comprehensive care was dealing with
18 the whole person. That is why we tend not to talk about
19 haemophiliacs but a person with haemophilia, emphasis on
20 "the person".

21 They had a comprehensive team which included an
22 orthopaedic surgeon, a clinical nurse specialist,
23 a counsellor, psychologist and so on, and it was people
24 like that who built that up who were so shattered, the
25 doctors and nurses and all concerned when this came into

1 kept out.

2 A. I have never heard.

3 THE CHAIRMAN: You don't remember that?

4 A. Not as a matter of policy. I would have remembered that
5 if that had happened, if that had been from the society.
6 That was the general mood of the haematologists, let it
7 be said, as I referred to the annual meeting which we
8 had with Professor Bloom and the like, Doctor Charles
9 Forbes. Their mood was until we knew more about it --
10 this was very mysterious until we knew more about it.
11 It was better to carry on with treatment because it had
12 such a major effect on the life-style of people with
13 haemophilia so that would be it. But I have never heard
14 that as an official policy.

15 THE CHAIRMAN: Sorry, I interrupted you.

16 A. No, I was just going to add my personal note to finish
17 that particular point. I had the very painful
18 ~~experience of conducting~~ the funerals of half the
19 members of the executive committee of the society. Of
20 a committee of 12, in the course of two years
21 I conducted the funerals for six which is an indicator
22 about the kind of the size of the problem at that
23 particular time that the life expectancy, that was in 89
24 to 91, the life expectancy was still so limited.
25 But then of course it was at this time when I was

1 meeting, we were meeting David Owen who was Minister of
2 Health and I am very glad to hear that you are going to
3 meet him because he will be able to speak for himself
4 because he did actually -- I expect you heard all this
5 before. When I met him in 1975 he received us very
6 sympathetically and he promised that he would see to it
7 that the Government policy became for self-sufficiency,
8 and he actually put aside money for that to be so.
9 I expect you have heard that before.

10 THE CHAIRMAN: Indeed.

11 A. I saw interestingly a letter, I do not know if you have
12 on the files. It is from David Owen to John Moore who
13 was the secretary at the time. This let it be said was
14 1987.

15 THE CHAIRMAN: We do have that.

16 A. Do you have that? Where he threatens to if you don't get
17 a satisfactory answer he is going to take it to the
18 ombudsman.

19 THE CHAIRMAN: That was of course after he had ceased to be
20 a minister and came back and discovered that we were not
21 self-sufficient.

22 A. I expect he will tell you all about that.

23 THE CHAIRMAN: I am sure he will.

24 A. He is able to speak for himself. That to him, he had
25 promised -- and he went away from that department to the

1 Foreign Office expecting that to happen and in 87 he
2 discovered it had not.

3 THE CHAIRMAN: I think what now seems to be emerging is that
4 the money which he was speaking about in 1975 was
5 devoted to the transfusion centres in order to maximise
6 the amount of plasma.

7 A. Yes.

8 THE CHAIRMAN: What probably happened and for some reason
9 does not seemed to have been grasped is that Elstree
10 couldn't process it.

11 A. That's it.

12 THE CHAIRMAN: That is what had brought the thing to
13 a standstill.

14 A. Our expectation was that the money was going into
15 Elstree for fractionation, it is another matter the
16 supply of plasma but then that's somebody else's
17 problem. We were only concerned with the actual
18 fractionation of the product, but then even that -- I
19 will not go into that now -- as you have heard even that
20 was not as purified as one might have expected the BPL,
21 at Elstree.

22 THE CHAIRMAN: Then there was the devastating report in
23 1979.

24 A. Absolutely. Here all this is emerging you see, and so
25 my main thesis on it all is is it goes back to

1 David Owen, that if what David Owen had proposed and
2 promised in 19 -- if that had happened the situation, we
3 can't all be prophetic about these things, but there is
4 a very very strong indication that the majority of these
5 problems would have been eased. So the big question is:
6 what happened to David Owen's money? And then it goes
7 on from there.

8 THE CHAIRMAN: I think we know what happened to the money.

9 What did not happen was that anything was done about
10 Elstree at that time.

11 A. Absolutely. I stand corrected. Yes, that is the point.

12 But then of course, going on from that David Owen set
13 aside £500,000 or something. That was a starter. That
14 was not expected to solve the whole problem. The
15 principle he was promising was that Elstree would be
16 restored to the points, developed at the points where it
17 would be self-sufficient. So the fact the 500,000 was
18 diverted is really not the significant bit. The
19 significant bit is David Owen, as he will testify,
20 expected monies to be available, and that was a starter,
21 to make us self-sufficient. And to me that is the crux
22 of the problem, that all these distressing testimonies
23 we will be hearing are the result of the Government's
24 failure to provide those proper facilities, and I don't
25 think that can be emphasised too strongly.

1 And then you go on, and the Haemophilia Society has
2 presented what I think is very comprehensive statements
3 for the inquiry and the Macfarlane Trust, so I will not
4 go into all of that there, but they do trace, and
5 I endorse that, they trace the history of our
6 relationships with successive administrations where it
7 is fighting all the way.

8 I mean, the Government, we expect the Government to
9 govern but perhaps we are naive in the political sense.
10 We expect the Government to be on our side and fighting
11 for us. But it was fighting all the way. If you go
12 through it all, the kind of heat treatments, you have to
13 fight them for that. When you come to the kind of
14 surrogates testee, you have to fight them on that. You
15 have to go and explain to them how there is going to be
16 another transformation.

17 The society's efforts have been diverted from the
18 personal care of people of haemophilia for which it
19 exists. The resources have had to be focused on
20 adopting a campaign involved which was never the
21 intention at all when the society was founded. And then
22 as for -- I mean, I had better not warm to the theme
23 because it would take too long but our experience of
24 campaigning for compensation and recompense is
25 unbelievable if you see it in cold print. How you

1 again, you have to fight the Government every line of
2 a campaigning document and then in the end we are not
3 going to call it compensation because we are not at
4 fault, says the Government. But setting that aside
5 whether they were at fault or not in knowing this could
6 happen, I set that on one side, they were certainly at
7 fault in not putting into effect David Owen's
8 recommendation and the like, and I think the Government
9 stands indicted on that particular point.

10 But even when you come to talk about recompense,
11 I mean the history of all that, we need to cast our
12 minds back to the time when Macfarlane came into
13 existence in the name of Professor Archie Macfarlane.
14 That was again because taking the historical
15 circumstance in common parlance the Government had us
16 over a barrel. Because the life expectancy was so short
17 many were minded to take it to the limit because we
18 thought it had a good case for legal action but the boys
19 and the men weren't going to be here to see it, and they
20 made that first offer of £10 million. We took it as
21 a starter. I remember Frank Field rising in the House
22 of Commons on the day when the minister made the
23 statement that this £10 million was going to be made
24 available. I remember Frank Field standing up in the
25 house and saying, "I must congratulate the Secretary of

1 State on being able to persuade the Haemophilia Society
2 to accept £10 million. We accepted because, as we were
3 saying at the time, it was a start. It enabled us to
4 get going. It helped us to meet an immediate situation.

5 But then we had to go back and fight again. They
6 changed the Secretary of State and the like and we had
7 to fight the case against so we had MSPT1 one payment.
8 To form an analogy it was like getting blood out of
9 a stone.

10 THE CHAIRMAN: It would not be the first time in history
11 that non-governmental organisations have been in advance
12 of governments of course.

13 A. Thank you. Then special payment one and then we had to
14 be back. I remember saying to Kenneth Clarke when he
15 was sitting in the seat that when he graciously made
16 this offer, it was not an offer, it was a statement,
17 that was it, but I said to him, "Are you expecting to
18 invite me back every year to make a similar..." He
19 said, "No, not at all, not at all."

20 But I am just emphasising the fact it has been
21 a struggle all the way along the line and I just want to
22 place that on the record there.

23 In my own view Macfarlane was established at that
24 particular time to serve a particular purpose. In my
25 own view -- I can only speak for myself now because I do

1 not hold an appointment with the trusts, but my own view
2 is that the whole matter needs reviewing because it was
3 formed at a time when the expectation of life was --

4 THE CHAIRMAN: That may be one of the tasks which fall to
5 us.

6 A. Yes, quite.

7 THE CHAIRMAN: That is most helpful.

8 A. Thank you.

9 THE CHAIRMAN: Thank you very much. Again, you would not
10 mind if we come back to you, Mr Tanner.

11 A. I would be very pleased to do so.

12 THE CHAIRMAN: Thank you. Just before we break up it may
13 help if I announce that our next evidence session will
14 be on 11th July at 9.30 in the morning. Lord Owen will
15 be giving evidence. Thank you very much.

16 (11.40 am)

17 (The Hearing Adjourned)

18