## Thursday, 14th June 2007

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2 (9.30 am)

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- 3 THE CHAIRMAN: We seem to be complete. Mobile phones turned
- 4 off. Our first witness is Lord Jenkin.
- 5 THE RIGHT HONOURABLE LORD JENKIN (called)
- 6 THE CHAIRMAN: Thank you very much for coming, Lord Jenkin.
- 7 We have your statement, so we can take that as read,
- 8 I take it.
- 9 A. It seemed to be rather a waste of time to read it all
- 10 out to you.
- 11 THE CHAIRMAN: Yes, indeed. You became Secretary of State
- in 1979 and went through to 1981 when you were moved to
- 13 another department?
- 14 A. Yes, September 1981, yes.
- 15 THE CHAIRMAN: And I think your Minister of State was
- 16 Dr Gerard Vaughan?
- 17 A. Yes.
- 18 THE CHAIRMAN: And you were content to leave the day-to-day
- 19 administration in relation to health to him?
- 20 A. Some issues on health. He is a doctor.
- 21 THE CHAIRMAN: Yes.
- 22 A. And he knew a lot more of course about the medical
- 23 aspects than I ever would and particularly he was
- 24 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.
- 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
- 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
- that from time to time, which might have perhaps been
- once or twice a month, some particular development or

- 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
- 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
- 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.
- I think the source by then had been identified and,
- 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
- infection relating to HIV as far as you remember?
- 15 A. That all arrived later. My successor, Norman Fowler,
- now Lord Fowler, he had to pick up the baton on HIV
- 17 because it had become then a major international
- 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
- 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
- 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
- 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
- of plasma, but that the laboratory at Elstree wasn't

- 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
- 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
- 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
- I am not quite sure why -- you may ask him -- but he
- persuaded me to go along to one of their meetings and
- I was quite horrified because I had had absolutely no
- 17 contact with this subject at all since I had left the
- 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.

And I began to become interested at that stage and it 1 was subsequently that one of the sufferers, I think 2 I mentioned him in my report, GRO-A from Scotland, 3 said, "But look, you were Secretary of State at the 5 critical time, could you go back and look at the papers and see if you can find any evidence which might support our case for some form of entitlement to compensation?" And I felt it was a duty I owed them because it is 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 see the permanent secretary, and perhaps, looking back 12 on it, I should have gone to him first, that is the 13 14 normal channel. I went to the minister in the House of Lords, Lord Warner, and that wasn't very successful. 15 16 But when I went to see the permanent secretary, Sir Nigel Crisp, now Lord Crisp, we got the thing back 17 18 on the right track. But it was then that Sir Nigel -and I remember his words very clearly and I quoted them 19 20 in my statement: 21 "Sir Nigel made it clear to me that all the files that bore upon the issue of contaminated blood products 22 23 had been destroyed."

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And he said the reason was they had settled the HIV

cases, compensation had been paid, and that it therefore

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

contaminated blood.

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- So what I have been doing since then is to ascertain and to satisfy myself, and I am satisfied beyond all doubt, that from the middle of the 1980s the department was very well aware of non-A, non-B hepatitis, as it has become Hepatitis C, and that they were well aware that that was one of the consequences of the transfusion of
- My immediate request -- reaction to Sir Nigel was,

  "But surely they knew that there were these other

  sufferers suffering with hepatitis who had suffered in

  exactly the same way as the HIV. Why just because you

  have settled the HIV cases was it decided to destroy the

  files?" And Sir Nigel's answer, "I'm afraid that's what

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

- 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.
- 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
- and I had a series of parliamentary questions, the first
- 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. | 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,
- 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,
- 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
- 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
- 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
- sent this latest batch, is that this is all that they
- 15 have been able to find, and Caroline Flint said much of
- 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
- 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
- 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
- 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
- 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
- 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
- a while ago. Non-A, non-B was what was thought of as
- 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
- 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 WILLETTS: 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,
- 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
- 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 WILLETTS: 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
- try to become more self-sufficient, and this is where
- the self-sufficiency debate comes in.
- 14 A. Yes, I don't remember -- and I have to say it does not
- 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 WILLETTS: 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
- 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
- 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
- admitting any liability, and yet the basis of the HIV
- 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
- 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
- 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
- 4 a lot more detail than I intend to go into today. A lot
- 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 Heydn Lewis, who is
- 11 a constituent of mine, who is sitting at the back came
- to see me and raised this issue with me.
- 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
- 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
- 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 are when you are trying to get information. A lot of it 2 was done through parliamentary questions, a lot of my 3 questions are answered very late, often over a month 5 late, which I believe is actually a breach of the House of Commons' rules, and often the information given in answer is -- could be said to be misleading, is often incomplete, sometimes they don't answer the questions at 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.
- And it was in contrast -- one of the other issues I 12 have been dealing with as a constituency MP relates to 13 the Department of Work and Pensions. And whilst I often don't agree with -- in fact pretty much always don't 16 agree with what they are telling me, on the whole they are better at providing information than the Department 18 of Health. So I think having the contrast between the two departments has really highlighted for me actually 20 how -- I would even go so far as to say secretive the Department of Health is being in terms of the 21 information that they will provide. 22

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

- 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
- 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
- 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.
- 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:
- "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
- 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 WILLETTS: 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 WILLETTS: -- purchase hub of some sort.
- 14 A. Just a very incomplete answer and not even indicating
- there was something else I should have been asking
- 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
- I then put in 10 more parliamentary questions trying to
- 25 find out about the -- what had been done to boost

- domestic production in the UK to try and achieve
  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.

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- Again, I tried to piece it together from other sources, but it could be quite difficult, but I think the evidence does suggest that, despite the fact that the Government did have a self-sufficiency policy, the money or some of the money that was referred to in one of David Owen's parliamentary questions in the 1970s talks about putting money into boosting production of I think it is called -- is it AHG, which is factor VIII, in the 1970s, and then an answer that I got talks about the same amount of money being -- with almost exactly
- 25 donations.

to the regional transfusion centres to boost blood

the same wording but talking about it being transferred

- 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
- generating more blood donations but actually there is
- 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

- on is around documents that have been destroyed, and as 1 far as I can see there are four different batches of 2 documents that have been destroyed or were thought to 3 have been destroyed.
- The first one is the documents that the department now says they have recovered from unmarked files or whatever in the basement. The second one is the minutes of the advisory committee on virological safety of 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 papers were destroyed when he moved from that ministry 12 in the 1970s; when he went back to ask for them I 13 14 understand he was told they had been destroyed.

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

- 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
- 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
- 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
- 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
- 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
- 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
- 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
- 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
- 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,
- 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
- their files if they then discover these 4,000-odd,
- 5,000-odd documents less than a year later?

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

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

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

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

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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 suggesting that they did it on purpose particularly but 12 it just doesn't give a good impression that actually of 13 all these documents the group that was picked was the one that was the smallest number and also for non-A, 16 non-B hepatitis I don't think that 1970 to 1985 is probably the crucial time period to do it. If they were going to do a really proper, thorough investigation of that particular subject matter then you needed to 20 include after 1985 as well, which is when testing was developed and it was identified and people were tested 21 for it and so on. 22

> So that type -- if you were going to pick the timeframe 1970 to 1985 then the obvious subject to look 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
- 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
- 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

- 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
- 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
- there is obviously some work that has been done on all
- of the documents. It is just that they are not
- 14 necessarily doing it as fast as they possibly could.
- But I mean, I think just overall I have found it
- quite illuminating. As a new MP I thought that --
- 17 I have been quite surprised at quite how reluctant they
- 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

- 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,
- 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
- found out that when Elstree was regarded as being
- somewhat deficient in some way or another did the BTS,
- 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
- 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
- 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
- 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 WILLETTS: Just briefly, given the extensive research and
- 19 investigations that you have conducted you clearly have
- 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
- 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

- available to you that the department has. I think from 1 2 speaking to people who are affected by this that one of 3 the main things they want to know is actually what went wrong, who knew what at what time and how certain things were allowed to happen. I think without -- with 5 respect, I don't necessarily agree with Lord Jenkin that people who were infected with HIV have had closure as a result of the action in the 1990s because actually it 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 I think in terms of actually just literally knowing what 12 happened and understanding who knew what I think is 13 14 a really important thing. I also do personally think that finance is a big 15 16 issue. A lot of people who are affected are living on
- very low incomes. They were given pay outs in the early 17 18 1990s on the basis of life expectancy for HIV, people who were HIV positive in the 1990s, which was very short 19 at that period of time, and the fact that people are 20 still living sort of 17 years later, living with the 21 disease I personally think we need to revisit that as 22 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 WILLETTS: Thank you.
- 9 THE CHAIRMAN: Right, thank you very much, most grateful.
- 10 If anything arises at a later stage you have no
- objection if we come back to you.
- 12 A. No, not at all. Thank you very much.
- 13 ALAN BURGESS (called)
- 14 THE CHAIRMAN: Good morning, Mr Burgess, thank you very much
- 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
- 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.
- B 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
- so much treatment as a severe haemophiliac would have
- had. Bleeding episodes were managed by the hospital
- 17 using cryo until 1982 when a delay in the treatment
- 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
- I became infected with HIV and why I'm here today.
- 24 My life and that of my family was to change for ever
- on a morning in September 1985 when I received a letter

from my local haemophilia unit telling me that I had 1 2 contacted HTLV 3 now known as HIV as a result of being given contaminated factor VIII. I was numb with shock 3 but as my wife and I were unsure of what the 5 consequences were we asked for advice but were told I looked okay so there was no need to worry. And at no point were we offered any form of counselling. So we were basically left on our own, a very bewildered 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 three years I had been at risk of infecting my wife and 12 the wait for the results were unbearable thinking 13 I could have harmed the person I loved GRO-C 14

GRO-C

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

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

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

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

prognosis at that time was poor.

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

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

I then made a will and proceeded to put my affairs in order to prepare for what I thought would be my last couple of years. My health didn't really improve and I was off sick more times than I was at work and whilst in hospital I was being treated for one of the many of the infections I was told by my doctor that I had to give up work or I would be dead very soon as my body 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
- said Hepatitis C positive. Once again we had little
- 14 counselling and it was hard for the family to accept on
- 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
- 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
- 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 saw 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.
- 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
- 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
- a video camera in the front of the house and nothing
- 14 ever came to light. Unfortunately it wasn't done again
- 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
- go on holiday, because you get new windows people get
- jealous. It could have been because of Aids. I just
- don't know. Unfortunately it's not something you go

- 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
- my family very concerned for my emotional well being.
- I then became so depressed with the situation I had
- 12 a nervous breakdown and I was admitted to a psychiatric
- 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
- 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.
- I know I wasn't a nice person to live with. Doctor
- 5 Jekyll and Mr Hyde comes to mind. Me moving out had
- 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
- and I became very ill and I was told that I was in the
- 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
- 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
- I still feel cheated out of a life that would have meant
- 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.
- At the beginning of my statement I touched on the
  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.
- 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.
- In my mind it matters little where the factor was
- 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
- us was infected with what we thought was safe treatment
- 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
- of heart attacks things like that. It is just getting
- 13 through day to day life really.
- 14 LORD TURNBERG: 1has 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
- 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
- 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
- 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 WILLETTS: Alan, 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 WILLETTS: 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
- "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 WILLETTS: 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
- wife went to see haematologist and we were extremely
- 14 angry because that is not the first time we were treated
- 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
- seen a lot of people's testimonies, and I wasn't the
- 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
- 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

- 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 WILLETTS: 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 WILLETTS: May I ask one question about the waiver. Can

- 1 you just tell me, Alan, 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
- 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 WILLETTS: 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 WILLETTS: Thank you.
- 24 THE CHAIRMAN: Thank you very much, Mr Burgess.
- 25 A. Thank you, now I have my daughter sitting here. This is

- 1 Laura, 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 Laura has spoken is it all right if my friend
- 7 Gareth Lewis 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 LAURA BURGESS (called)
- 19 THE CHAIRMAN: I don't think we actually have your name.
- 20 A. It is Laura Burgess.
- 21 THE CHAIRMAN: Yes.
- 22 A. I was 11 years old when I was first told that my father,
- Alan Burgess, was HIV positive. Needless to say I was
- 24 devastated. All I could think about was why does this
- 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 Gareth Lewis and I am going to read this on
- 6 behalf of Laura:
- 7 "I was 11 years old when I was first told that my
- 8 father, Alan Burgess, 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
- 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
- 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

ask questions and I hated that because I would have to
lie about what was really wrong with my Dad as if he had
an embarrassing illness or done something wrong. So I

just wouldn't eat. It was easier that way.

When I was 15 my Dad had a nervous breakdown and was sent to a psychiatric hospital. I can remember he came out on day release from the hospital and his hands were shaking, he was really quiet, he wasn't himself at all.

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

- People just do not understand this illness and still the 1 2 stigma towards it continues.
- Two weeks later my parents separated. I can remember my Dad crying to me about everything. I had
- 5 never seen a man cry before, let alone my Dad. My
- parents didn't speak for a while and times were tough.
- There was talk of a divorce and I even stopped speaking
- to my Mum for a while because I blamed her for it all.
- My whole life was in ruins.

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10 I was sent to see another counsellor and this time 11 she did help me. She understood because she had a friend die of AIDS a few years before. It was really 12 nice talking to someone that understood. During this 13 14 time my Dad became really ill. He had been ill quite a few times before and has always been in and out of 15 16 hospital. But he has never been like this. He did not have a carer any more as my Mum did not live with him so 17 18 I took over this role. This was incredibly difficult seeing him in so much pain. Every time my Dad gets ill 19 20 I always wonder, 'Is this it?' This illness is so 21 unpredictable, you never know when it will happen, and

I've seen so many of my Dad's friends die of the same

thing. My Dad became so ill that he was hospitalised

and no one was able to see him. This was really hard.

It scares me every time he's ill and it's horrible to

- see him that way knowing that there is nothing you can
  do to help.
- Since then I have moved out of my parents' house.

  I turned to drugs for a while, got myself into debt and
  began self-harming. It was only when I met my current
  partner two years ago that I have finally been able to
  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.

THE CHAIRMAN: Thank you.

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

- 1 A. I have also been asked to read Sarah's statement. Is
- 2 that okay?
- 3 THE CHAIRMAN: Yes, please.
- 4 A. Okay:
- 5 "My name is Sarah Burgess. I am 27 years old and
- 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
- were on the TV and that's what everybody spoke of.
- 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
- 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.
- 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
- 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
- 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.
- After three years of going through hell they managed
- 25 to patch things up and move back with one another.

I now have a **GRO-C** daughter. The decisions I had to face along with my fiancee during my pregnancy could and should have been avoidable. We had to decide whether or not to have our embryo screened for haemophilia and what to do if it was a haemophiliac. Abort? Who is to say that in 20 years' time there is not a similar disease out there threatening the haemophilia community just as AIDS has? The Government screens blood now for things they know but nobody knows

what may happen in the future.

- We eventually decided not to have any testing done and let nature take its course. But we shouldn't have to play with nature, we shouldn't have to think so cautiously about our health. But I truly do not trust the Government or the health service after what they have done to keep us safe.
- My Dad is well at present but I haven't mentioned the numerous times he has been in and out of hospital for one thing or another. We have been told a few times that if this particular combination therapy, the drugs he takes, doesn't work, then there is really nothing else left.
- In my mind I have said goodbye too many times. This awful ordeal has affected all the children of all these men. It is about time we were given an apology too.

- 1 Sarah Burgess."
- 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 Sarah's statement, please. We have
- 5 copies of the others.
- 6 MR MEHAN: It has been sent to us, Laura, thank you.
- 7 THE CHAIRMAN: Thank you very much, Mr Burgess.
- 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
- 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
- the side of brevity because, as I said in the statement,
- I am very much aware that as I come to -- come before
- 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
- 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
- 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
- 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
- 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
- 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

- 1 altruistic mood in being very concerned about developing
- 2 countries, because those six, as you might imagine, were
- 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.
- 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. First of all I give my own credentials apart from those
- appointments I have held. My main credential is in
- 25 having the family connection through my son. As I say,

my family's acquaintance with haemophilia came through 1 my son who was born in 1955 and diagnosed as having 2 3 severe haemophilia A (less than 1 per cent factor VIII) by a spontaneous mutation, and he died in 1998. 5 During his life, he experienced the developing problem of haemophilia treatment and care. Here I repeat things which you have already heard. In 1955 there was no specific treatment for bleeding episodes, 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 everybody here with haemophilia will know all about 12 that. And then there is a very interesting little 13 14 element here. Russel's Viper Venom was carried in the pocket of people with haemophilia in those days as 15 16 a coagulant for excessive external bleeding, but that was about the measure of it; never move without your 17 18 Russel's Viper Venom. So then I am very anxious to communicate to you the 19 20 kind of the mood of people with haemophilia in those days because it was -- the future was blank. Life 21 expectation was very, very limited there in 1955. So, 22 23 as I say in my statement, we were greatly comforted by

the discovery of Cryoprecipitate Professor Judith Pool

in the United States, who I knew personally through the

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- World Federation, because I travelled with her, and that 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
- able to deal with that.
- 16 In the next step, as I say in my statement -- I will
- not read it word for word -- but the next step, and it
- 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
- 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
- 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	
1	them	about.

What there were was a very close relationship

between doctor and patients, and I know, speaking of our

own situation, the doctor concerned, Dr Katherine

Dormandy used to come any hour of the day or night to do

this particular infusion. And I think it is -- it

should not go unnoticed, in spite of what we are hearing

about in the developing years, it should not go

unnoticed the degree of dedication of those particular

doctors who after all were in a pioneer situation. It

was all a mystery in those days.

But I will testify again to the transformation which took place once the boys and men were taught how to infuse themselves, which is not a very simple thing unless you are taught how to do it. They were taught how to infuse themselves. They took their factor VIII home, had a little fridge to put it in. Everybody here will know all about this. They were able to treat themselves immediately and the world opened up because no longer need they have the kind of swollen joints which were the feature of all people haemophilia, my son included, no longer did they need that because, as every person with haemophilia will know, they can anticipate 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
- 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.
- 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
- by. They carried with them their little phials of
- factor VIII and their little kits, and wherever they
- 17 were in the world, in Brazil, in Japan, whatever, they
- were able to look after themselves. The important thing
- 19 is they were being weaned from their centre and this was
- 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
- at a later stage we have had a rather different picture
- 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
- about the disease and the effective treatments.
- 12 A. Absolutely, as did we all. So did the boys with
- 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
- 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 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
- 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
- of carrying on with treatment far outweighed any kind
- 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

- 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
- 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
- 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
- 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
- like that who built that up who were so shattered, the
- doctors and nurses and all concerned when this came into

- 1 their lives. I say -- I mentioned the case of my own
- 2 son, he is but one example, 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
- 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 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.
- 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
- 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 threats 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
- 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
- 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
- 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
- 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.

And then you go on, and the Haemophilia Society has 1 2 presented what I think is very comprehensive statements 3 for the inquiry and the Macfarlane Trust, so I will not go into all of that there, but they do trace, and 5 I endorse that, they trace the history of our relationships with successive administrations where it is fighting all the way. I mean, the Government, we expect the Government to 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 through it all, the kind of heat treatments, you have to 12 fight them for that. When you come to the kind of 13 14 surrogates testee, you have to fight them on that. You have to go and explain to them how there is going to be 15 16 another transformation. The society's efforts have been diverted from the 17 18 personal care of people of haemophilia for which it exists. The resources have had to be focused on 19 20 adopting a campaign involved which was never the 21 intention at all when the society was founded. And then as for -- I mean, I had better not warm to the theme 22

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unbelievable if you see it in cold print. How you

because it would take too long but our experience of

campaigning for compensation and recompense is

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again, you have to fight the Government every line of 1 2 a campaigning document and then in the end we are not going to call it compensation because we are not at 3 fault, says the Government. But setting that aside 5 whether they were at fault or not in knowing this could happen, I set that on one side, they were certainly at fault in not putting into effect David Owen's recommendation and the like, and I think the Government 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 minds back to the time when Macfarlane came into 12 existence in the name of Professor Archie Macfarlane. 13 14 That was again because taking the historical circumstance in common parlance the Government had us 15 16 over a barrel. Because the life expectancy was so short many were minded to take it to the limit because we 17 18 thought it had a good case for legal action but the boys and the men weren't going to be here to see it, and they 19 made that first offer of £10 million. We took it as 20 a starter. I remember Frank Field rising in the House 21 of Commons on the day when the minister made the 22 23 statement that this £10 million was going to be made 24 available. I remember Frank Field standing up in the house and saying, "I must congratulate the Secretary of 25

- 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
- 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
- was sitting in the seat that when he graciously made
- this offer, it was not an offer, it was a statement,
- 17 that was it, but I said to him, "Are you expecting to
- 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.
- 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
- be giving evidence. Thank you very much.
- 16 (11.40 am)
- 17 (The Hearing Adjourned)

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