

Penrose Inquiry

The following transcript is for Day 30 of the Oral Hearings of The Penrose Inquiry, held on 9th June 2011.

This session comprised two closed sessions during which a patient or relative gave evidence anonymously to protect their privacy.

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Thursday, 9 June 2011

(9.30 am)

FRANCES

Questions by MS PATRICK

THE CHAIRMAN: Good morning. Yes, Ms Patrick?

MS PATRICK: Sir, this morning we have Frances to give evidence.

Good morning Frances. I would like to start by letting you know who everybody is in the room today.

On the bench we have Lord Penrose and next to him Professor James, who is the medical adviser to the Inquiry. You obviously know Margaret who is seated beside you.

A. Yes.

Q. The two people closest to you at the front desk here are the stenographers, who are going to record what's said this morning and that will make up the transcript, which I think you know about.

A. Sure.

Q. Seated next to them is Maria McCann, who is the secretary to the Inquiry and then we have OliStempt who is in charge of the documents and as we go through your evidence this morning, some of the documents I refer you to will be shown on the screen in front of you and that's Oli's job to do that.

1 Seated beside me is Laura Dunlop, who is the senior
2 counsel to the Inquiry and behind her is Yasmin Shepherd
3 who is the paralegal working at the Inquiry in respect
4 of this topic.

5 On the front here we have the lawyers for the
6 interested parties to the Inquiry. The lawyers closest
7 to me are the lawyers representing the patients,
8 relatives and Haemophilia Society. In the middle we
9 have the lawyers for the health board and the Scottish
10 Blood Transfusion Service and the lawyers closest to you
11 are those acting on behalf of the Scottish Government.

12 A. Thank you.

13 Q. You are being known as "Frances" for today's hearing but
14 that's not your real name.

15 A. No.

16 Q. Okay. You helpfully provided a statement to the Inquiry
17 in respect of your father's infection with HIV and the
18 Hepatitis C virus as a result of treatment he received
19 for his haemophilia?

20 A. Yes.

21 Q. I wonder if you could have a look at WIT0040055, which
22 should be a copy of the statement which you provided to
23 the Inquiry?

24 A. Okay.

25 Q. I hope that you have a hard copy of this in front of

1 you?

2 A. I do indeed, yes.

3 Q. So as we go through your evidence, I'll refer you to

4 parts of this and it will appear on the screen but also

5 feel free to refer to your hard copy.

6 A. Okay.

7 Q. You tell us in paragraph 1 that you are 41 years old.

8 Is that still correct?

9 A. Still correct, yes.

10 Q. Still correct. You tell us that you are a [REDACTED]?

11 A. I am, yes.

12 Q. Could you tell us what type of [REDACTED] you are?

13 A. I work in [REDACTED].

14 Q. How long have you worked at that?

15 A. I have been doing that for a year and a half. Prior to

16 that I was [REDACTED].

17 Q. [REDACTED]. So how long have been been qualified as a [REDACTED]?

18 A. Since [REDACTED].

19 Q. Okay. Where did you study [REDACTED]?

20 A. [REDACTED].

21 Q. We know that you have two brothers?

22 A. Yes.

23 Q. Are they younger?

24 A. They are both younger than me.

25 Q. What's the age difference between you?

1 A. [REDACTED]

2 [REDACTED]

3 Q. You are aware, I think, that your younger brother
4 provided a statement to the Inquiry, which I will refer
5 you to later.

6 A. Yes.

7 Q. You are obviously here to tell us really your father's
8 story and the impact of this on you as a family. Could
9 you tell us a bit about your father? What was his
10 occupation?

11 A. [REDACTED]

12 Because of his haemophilia he couldn't go to school.
13 When he was diagnosed they wouldn't take people with
14 that severe haemophilia into school presumably because
15 of the risk of bleeding. [REDACTED]

16 [REDACTED]

17 [REDACTED]

18 [REDACTED].

19 Q. What did he enjoy doing in his spare time?

20 A. He was very active. He didn't let his haemophilia hold
21 him back. [REDACTED]

22 [REDACTED]

23 [REDACTED]

24 [REDACTED] he had a real zest for life.

25 [REDACTED]. And apart from

1 that he was quite a family man. So we did things as
2 a family, holidays.

3 Q. You said that he didn't manage to go to school. Did he
4 not manage to go to school at all?

5 A. No, he had some home tutors for a while but he had no
6 formal teaching and no qualifications.

7 Q. It sounds as if he didn't let this hold him back?

8 A. Not at all.

9 THE CHAIRMAN: [REDACTED]

10 A. [REDACTED]
11 [REDACTED]
12 [REDACTED]
13 [REDACTED]
14 [REDACTED]
15 [REDACTED]

16 THE CHAIRMAN: [REDACTED]

17 [REDACTED]
18 [REDACTED]
19 [REDACTED]

20 A. [REDACTED]

21 THE CHAIRMAN: You're dad must have been quite a man.

22 A. He was.

23 MS PATRICK: What year was your father born in?

24 A. [REDACTED].

25 Q. Thank you.

1 You tell us in paragraph 2 of your statement that
2 the Haemophilia A from which he suffered was severe?
3 A. Yes.
4 Q. That he had virtually none of his own Factor VIII.
5 I think we will see when we move through the medical
6 records that in fact he had less than 1 per cent
7 clotting factor. Is that right?
8 A. I believe so, yes.
9 Q. You say that he always resided in the Edinburgh area?
10 A. Yes.
11 Q. His treatment was at the Edinburgh Royal Infirmary?
12 A. Yes.
13 Q. Under the care of the now Professor Ludlam?
14 A. Yes.
15 Q. Was it always at the Edinburgh Royal Infirmary?
16 A. Always, yes.
17 Q. Even as a child?
18 A. Even as a child, yes. I think prior to DrLudlam it was
19 Dr Davies.
20 Q. I think we will see that from the medical records. Was
21 there a family history of haemophilia?
22 A. No.
23 Q. No?
24 A. No. I think it was a new mutation.
25 Q. You tell us in paragraph 4 about your father's treatment

1 for his haemophilia?

2 A. Yes.

3 Q. You don't know what age he was first treated with blood

4 products but you know that he was initially treated with

5 snake serum?

6 A. Yes.

7 Q. Which I think was a more common treatment quite a few

8 years ago?

9 A. Yes, when he was a child.

10 Q. Yes. Did he tell you about that himself?

11 A. He did, yes.

12 Q. You tell us that he was then treated with

13 cryoprecipitate when it first became available and then

14 with Factor VIII, when that became available. Do you

15 know how often he needed treatment as a child?

16 A. It was certainly every week. Sometimes it was several

17 times a week.

18 Q. So is it fair to say he spent a lot of his childhood in

19 the hospital?

20 A. I think so, yes, because he didn't get home treatment

21 until, certainly well after I was born because

22 I remember that.

23 Q. He didn't manage school, as you said. Did he tell you

24 anything else about how this affected his childhood?

25 A. I think it kept him away from other children. So you

1 know, he had an older sister, so -- and the local
2 children. It kept him away from -- he wasn't part of
3 a school or a group but he was quite a sociable person,
4 so, you know, he got on.

5 Q. He managed to make up for that?

6 A. Yes.

7 Q. I wonder if you could please have a look at
8 WIT0040541, which is a record of treatment that your
9 father received in August 1969. He has a bleed of the
10 left ankle and we will see in the history that he
11 developed a deep severe pain in his left ankle and the
12 ankle was sensitive to any movement. It eased slightly on
13 complete rest but the pain gradually increased during
14 the evening. He then contacted the haematology
15 department and was admitted to the ward.

16 So it looks there like he obviously tried to
17 alleviate the bleed himself by resting the ankle first?

18 A. Yes.

19 Q. Was that something --

20 A. That would be in character. [REDACTED]

21 [REDACTED]

22 [REDACTED] he didn't rush into the
23 hospital.

24 Q. We can see in the next section that he was given two
25 pints of fresh-frozen plasma by an intravenous drip.

1 Unfortunately the pain still persisted for a while and
2 he was then given more fresh-frozen plasma. It's noted
3 that he was also given Piriton prophylactically and
4 despite that he still developed a transfusion reaction
5 to the treatment and this was settled with a further
6 dose of Piriton. The pain gradually eased and he was
7 well enough to go home the next morning.

8 Did your father quite often have a reaction to his
9 treatment for his haemophilia?

10 A. That's not something I remember an awful lot about. I
11 can't think of him having a reaction to his home
12 treatment but he was already getting home treatment by
13 the time I was nine or ten. I don't remember a lot
14 prior to that.

15 Q. Thank you. I wonder if you could look at WIT0040542.
16 This is in April 1971, [REDACTED]
17 [REDACTED], and your father has developed a mild bleed of his
18 left knee and has received eight packs of
19 cryoprecipitate as an outpatient. At that point you
20 will see from the third paragraph that your father is
21 very anxious to have prophylactic weekly injections of
22 cryoprecipitate to see if it can mitigate the number of
23 spontaneous joint bleeds from which he suffers.
24 Dr Davies is there saying that he would be willing to
25 try this on an experimental basis and he notes that:

1 "The patient appreciates that there is a small risk
2 of serum hepatitis or even developing an antibody to
3 Factor VIII from the transfusions of blood products, but
4 I think that this will not be greater than the risk he at
5 present has consequent on frequent transfusions on
6 admissions."

7 So this suggests a number of things: that he was
8 having many bleeds?

9 A. Yes.

10 Q. That he was very keen to try and resolve them --

11 A. Yes.

12 Q. -- with regular treatment, and that he was prepared to
13 go ahead with those treatments, even if there was a risk
14 to him at that time of hepatitis. It is described there
15 as a small risk or the risk of developing an antibody to
16 the Factor VIII?

17 A. Yes.

18 Q. If we look at WIT0040543, this is simply showing that
19 your father has now started receiving Factor VIII as
20 a treatment for his haemophilia and he is being provided
21 with a supply of this to take on holiday, and he is off
22 on the Continent on holiday by car.

23 The medical records show that in the early part of
24 the 1970s your father was treated sometimes with
25 Factor VIII and sometimes with cryoprecipitate. I don't

1 propose to show you this but for the record WIT0040546
2 shows treatment in November 1973 with Factor VIII for an
3 acute bleed of the left elbow and WIT0040547 shows
4 treatment in April 1974 of eight packs of
5 cryoprecipitate for a bleed into the right calf.
6 I wonder if we could now turn to another document which
7 gives us some idea of the extent of the treatment which
8 your father received, and that is WIT0040549.

9 This is a letter from the Sun Life Assurance Society
10 Limited to Dr Davies and it's seeking a report from him
11 as your father has obviously applied for life assurance
12 at that time. If we move over to the next page, which
13 ends 0550, this shows us the medical information which
14 Dr Davies has provided to the life assurance company.
15 As you will see he says at that time that he has known
16 him for 15 years, and in section 4 that he is in good
17 health, except for his haemophilia.

18 Just in relation to that, I think you said in
19 paragraph 3 of your statement that your father was
20 diagnosed at a very young age with his haemophilia and
21 at that time his mother was told that he would be
22 unlikely to live beyond two years of age?

23 A. That's what he told me.

24 Q. Yes. So looking on to section 5, Dr Davies states:

25 "This man is a severe haemophiliac with

1 a Factor VIII level in the plasma of less than
2 1 per cent. He does not have an inhibitor to
3 Factor VIII. He has had innumerable bleeds, mainly into
4 joints, over most of his life. He now can
5 self-administer the concentrated Factor VIII which he
6 does at the haemophiliacentre ..."

7 I think it's -- I can't quite read that word but:
8 "... in the Royal Infirmary on an outpatient basis."

9 So your father by that time has reached the stage
10 that he can go into hospital and give himself treatment
11 there:

12 "Soon when a dried product is freely available he
13 will do this at home. He has moderate joint deformity
14 from bleeding of his knees, elbows and less so of other
15 joints - see below."

16 If we look below:

17 "Apart from his haemophilia, he is very fit.
18 Nonetheless, this disorder constitutes a definite
19 morbidity and mortality risk increase, even with modern
20 therapy."

21 How did the bleeds affect your father?

22 A. They slowed him down. He had to stop and stay --
23 I mainly remember the times when he was treating himself
24 at home. So he would say, "Right, I have got a bleed",
25 and we would have to get the stuff out and he would give

1 himself the injection and he would rest. I think he
2 would have been busier and more active if he could have
3 been -- and they caused him pain. So he would look
4 drawn. He didn't complain of pain really but he would
5 be in pain.

6 Q. Did he start to have trouble from his joints on a longer
7 term basis as a result of the bleeds?

8 A. Yes, he developed arthritis because of it. Bleeding
9 into joints is quite irritant. So I don't remember him
10 not having swollen joints. The whole time that
11 I remember him he had slightly bent joints and swelling,
12 especially in his knees and elbows.

13 Q. But from what you tell us, it sounds as if he just
14 carried on with life --

15 A. Yes.

16 Q. -- regardless?

17 A. Yes.

18 Q. Did he receive treatments at times from consultant
19 orthopaedic surgeons? If you do not know, please just
20 say.

21 A. Not that I recall. So -- I don't remember him ever
22 having anything done. Whether or not he saw someone.
23 He is almost certainly going to have had consultations.
24 But I don't remember him ever having any procedures.

25 Q. No. Physiotherapy?

1 A. Yes.

2 Q. He used to go for physiotherapy?

3 A. Yes.

4 Q. Did you see him wearing splints at all?

5 A. Yes, he had various splints. His elbow would sometimes
6 be held in a thing -- in a sort of cast thing. Yes, he
7 had splints for various joints.

8 Q. In relation to his elbow, we will come back to this
9 document, but if we could turn to WIT0040564, if we
10 could scroll down a bit, please. This is a letter from
11 Mr Chalmers, consultant orthopaedic surgeon, dated
12 21 December 1979 to a DrStirling at the department of
13 haematology at the Edinburgh Royal Infirmary. Your
14 father has obviously been referred to him again, he
15 says, and he notes that he presents a very difficult
16 problem:

17 "The only options available surgically for his left
18 elbow are synovectomy, arthrodesis and arthroplasty."

19 Your father is not prepared to consider arthrodesis
20 because he feels a stiff elbow would prevent him from
21 working?

22 A. Sure.

23 Q. This is presumably in ?

24 A. Sure.

25 Q. "Arthroplasties have not yet developed to the point

1 where one could recommend their use in such a young man
2 and synovectomy might gain very little because his joint
3 is so extensively destroyed, but nevertheless I think
4 the gains might be significant and this is the one
5 procedure that is really worth a trial."

6 Your father is not very keen on the prospect of such
7 a limited objective and is going away to think about it:

8 "Meanwhile I have provided him with a new splint for
9 his elbow which he can wear when he is not working."

10 So we can see that already by 1979 your father has
11 suffered significant damage to a joint. Do you know --
12 I appreciate you are very young at that time -- if he
13 had that surgery?

14 A. I don't think he did, I don't remember.

15 Q. Thank you. Could we go back, please, to the next page
16 of the form that we were looking at for life assurance,
17 which is WIT0040551.

18 This shows a list of the treatments which your
19 father needed between 10 September 1973 and
20 19 February 1975, as carefully listed by Dr Davies. So
21 in this 17-month period this shows that your father
22 needed treatment for bleeds 48 times, which was working
23 out at just under three a month, so it tallies with what
24 you are saying about virtually every week your father
25 was needing treatment for a bleed?

1 A. Yes.

2 Q. I don't suppose you know if your father was able to get
3 life assurance?

4 A. Yes.

5 Q. He was?

6 A. Yes.

7 Q. So he did manage?

8 A. Yes.

9 Q. Do you know if he had to pay more for it?

10 A. Yes.

11 Q. Was that due to his haemophilia?

12 A. Yes.

13 Q. Could I refer you back to your statement, please, to
14 paragraph 4, WIT0040055?

15 You have touched on this already:

16 "By the time I was ten years of age, he was
17 definitely being treated with Factor VIII and on home
18 treatment as I recall that. I don't think he was treated
19 prophylactically but he would require treatment
20 approximately once per week."

21 As we have already said.

22 A. Yes.

23 Q. "He did bleed spontaneously and often into joints.
24 I know that he did attend Edinburgh Royal Infirmary
25 regularly and DrLudlam was his haemophilia consultant.

1 I know that my father was happy with the care provided
2 by DrLudlam and he had a lot of time for him."
3 A. Yes.
4 Q. So they obviously had a good doctor/patient
5 relationship?
6 A. They did.
7 Q. I wonder if you could, please, have a look at
8 WIT0040553. This is in relation to home treatment.
9 A. Okay.
10 Q. As you will see, this is a letter from Dr Davies,
11 dated June 1976, recording that your father is now going
12 onto on demand home treatment for joint bleeds for
13 haemophilia and he will be given a supply of Factor VIII
14 for self-administration and he is competent to manage
15 this procedure himself, no doubt thanks to all his
16 practice in the hospital?
17 A. Yes.
18 Q. He copies this to Dr Cash at the Blood Transfusion
19 Service and at the bottom right:
20 "Dear John, [your father] is joining the home
21 treatment programme with effect from 22 June 1976."
22 A. Okay.
23 Q. So as you say, it wasn't prophylactic treatment
24 initially, it was treatment in response to bleeds.
25 I think, as most people had to do, he kept records of

1 his treatment at home. Could you, please, have a look
2 at WIT0040555. Is this your father's writing?

3 A. No, it's my mum's.

4 Q. Oh, it's your mum's?

5 A. My Dad's writing was appalling.

6 Q. Was it?

7 So this shows some treatment that your father gave
8 himself at home in 1977 for spontaneous bleeds of
9 various joints and records how much he used, and you
10 will see that the top one there is the 19 April 1977.
11 If we look over the page at the document ending 0556, we
12 will see a more detailed record of that one treatment.
13 You will see half way down, the date is 19 April 1977
14 and this shows that the bleed was in the knee and that
15 this was a moderate bleed and the cause of the bleed was
16 spontaneous.

17 It tells you the time of treatment and further down
18 how long it took for the infusion of the treatment, the
19 batch numbers and the results of the treatment and any
20 side effects, and then it says:

21 "Was further therapy required?"

22 It is ticked there, the "following day," which from
23 the previous document we looked at, we could see
24 actually that he did require treatment again. And there
25 were individual sheets like this for every treatment

1 that your father gave himself at home. So your mother
2 obviously assisted him with the record-keeping?

3 A. Yes, there are probably ones in there with my writing
4 later on.

5 Q. Did you assist him too?

6 A. Yes.

7 Q. What happened to these records of his treatment?

8 A. No idea.

9 Q. No idea?

10 A. No.

11 Q. What did your father think of treatment with factor
12 concentrate?

13 A. I think he was glad that he could do it at home.

14 Q. Yes.

15 A. We didn't really talk about it terribly much. I was
16 quite young when he explained to me what it was and how
17 to make it up, and I used to help him make it up because
18 it took ages to dissolve. So you had to sit and do this
19 with it and I think I was about ten -- he taught me how
20 to do it. So I was ten when I gave my first IV
21 injection.

22 Q. That's impressive. Did your father feel that this
23 treatment changed his life expectations?

24 A. Yes, yes. I think he, you know, believed that this was
25 going to keep it under control as much as possible,

1 although he was realistic that he had severe haemophilia
2 and that he did bleed regularly. He knew that there
3 were risks of bleeding into places other than his
4 joints, but, no, he had an optimistic outlook.

5 Q. I think that's coming through from what you are telling
6 us about him. Do you know if your father was warned of
7 any risks associated with his treatment for haemophilia?

8 A. I can't remember any specific conversations that he and
9 I had but from what I know of my dad, he would have
10 asked. So he was big on being fully informed and wasn't
11 afraid to ask questions. So I expect that he knew
12 whatever risks were known at the time, he would have
13 known about too.

14 Q. Right. Okay. So you can't say if you know that your
15 father specifically knew of any risks associated with
16 treatment with Factor VIII?

17 A. I don't remember talking to him about it.

18 Q. In relation to this, I wonder if you could have a look
19 at document WIT0040566. I'm sorry, it's not a very
20 clear copy but I'll try and read it along with you.
21 It's a letter from DrLudlam and it's actually to your
22 father, I think, enclosing two letters. This is about
23 your father taking Factor VIII on holiday. So I wonder
24 if these might have been letters to explain his
25 treatment for the fact that he had these products with

1 him, but that's surmising.

2 A. When I was a teenager we went to America -- yes, we went
3 to America, and I think he said something round about
4 then about treatment -- to avoid treatment -- where to
5 go if he had a major bleed. Is that what this is?

6 Q. This is about avoiding commercial product if he can
7 while he is away. Does that ring a bell?

8 A. Yes, yes, I remember that because he told me in case it
9 happened and he wasn't able to do it, if he was
10 unconscious. He told me so that I would know but
11 I remembered at the time.

12 Q. Right. As you will see, he has given him two letters
13 and he hopes that they are satisfactory for his needs:
14 "I understand you would like some Factor VIII to
15 take with you to... "
16 We think that's "America":
17 "If supplies permit, we will try and let you have 40
18 bottles on ..."
19 Well, 40 bottles:
20 "Please could you phone in a day or two in advance
21 to make arrangements to collect the Factor VIII. If
22 possible, whilst in ... could you try and avoid the use
23 of commercial Factor VIII... "
24 THE CHAIRMAN: "Concentrates" is it?
25 MS PATRICK: Yes:

1 "... concentrates, as they may well give you
2 hepatitis. I would suggest that you try and obtain
3 cryoprecipitate for minor bleeds. Obviously, if you
4 have a major bleed, then you will have to take the
5 advice of the local ..."

6 Well, hospital staff or local staff:

7 "... at the haemophiliacentre and possibly have
8 commercial Factor VIII. It seems some time since I saw
9 you at my clinic and I would be grateful if you would
10 come and see me in September."

11 That's presumably after his holiday. So that's
12 something you obviously remember because your father
13 involved you --

14 A. Yes.

15 Q. -- in that.

16 A. Yes.

17 Q. I wonder if we could turn now to your father finding out
18 that he had acquired the HIV virus. This is in
19 paragraph 5 of your statement, which is WIT0040056.

20 You say:

21 "My father was told in 1984 that he had HIV.
22 I believe he knew he was being tested for HIV. I am not
23 sure how he was told he had HIV but I do believe it was
24 DrLudlam who told him. I was 15 years of age at the
25 time when my father learned of his diagnosis and

1 informed me."

2 A. Yes.

3 Q. You say there, 1984. I take it if the medical records
4 show, it might have been 1985?

5 A. No, it was 1984.

6 Q. It was 1984?

7 A. I looked at diaries from the time and he told me on
8 21 December 1984.

9 Q. Right, okay. How soon after him being told do you think
10 that was?

11 A. I would imagine it was very soon. There had been
12 something on the radio a week or two weeks prior to that
13 about haemophiliacs being affected by HIV in the blood
14 products, because that was the first I heard of it and
15 then -- so, because when he told me, it wasn't
16 a complete out of the blue shock. So my understanding
17 of the situation was that news was broken, and then
18 I was told a short period of time afterwards, which may
19 have been a fortnight, and at that time I thought,
20 "Well, I wonder if he has been and gone and got tested
21 since hearing that". So I don't know if he was tested
22 before that and he hadn't told me but I don't -- that's
23 when he told me and I believe it was a short time.

24 Q. Yes. So was that your first awareness of the virus or
25 of the fact --

1 A. I don't think so because there had been news from the
2 States.

3 Q. Before that?

4 A. Before that, but I hadn't really connected it with --

5 Q. People with haemophilia?

6 A. Yes, with blood products. I didn't really pay too much
7 attention to it.

8 Q. So it must have been end of November/early December when
9 you first heard this --

10 A. Something like that.

11 Q. -- item on the news, connecting HIV virus and people
12 with haemophilia?

13 A. Yes.

14 Q. Your family life at the time: your Dad was working at
15 his business. Did your mother work?

16 A. No.

17 Q. No. You were at school?

18 A. Yes.

19 Q. Your brothers, were they both at school about then?

20 A. No, let me see. My next brother down was definitely at
21 school. My other one probably hadn't started yet. He
22 would be at nursery.

23 Q. Right. You say you believe that he knew he was being
24 tested for HIV. Why do you think that?

25 A. I think that because -- for a couple of reasons. One,

1 there was this news article. We discussed it a bit at
2 the time. Then he came back with a positive result. So
3 my understanding was that he was tested at that time.

4 The other thing is my belief in my Dad's -- he knew
5 so much about his condition and I would be surprised if
6 he had been tested and didn't know about it. Now, that
7 might sound like a slightly naive thing to say but if he
8 knew it was possible, he would have asked about it.

9 Q. So you think he would have heard about it and raised it?

10 A. I believe so. If he had heard about it, he would have
11 asked about it.

12 Q. Yes. You tell us in paragraph 14 of your statement,
13 which is over the page, ending 0057, that:

14 "I know that my father was told when he was diagnosed
15 with HIV that he would have contracted this through
16 blood products. My father didn't have a choice about
17 using blood products throughout his life because he had
18 severe haemophilia."

19 A. Yes.

20 Q. "He knew that he was being tested for something else at
21 the haemophilia clinic and that was when there was
22 a discussion about non-A non-B hepatitis."

23 Which we will see a bit later on from his medical
24 records:

25 "I'm pretty sure he consented to this testing."

1 Is that in relation to HIV --

2 A. To either, you know.

3 Q. As you have told us just before:

4 "In any case he would have, because he was the sort
5 of man who wanted to know everything about his health
6 and treatment."

7 Could we have a look, please, at WIT0040608, which
8 is a clinical note actually for later on but does look
9 back at the time around your father's diagnosis. We
10 will actually come back to this document later, about
11 what it is in fact discussing, but if we could look at
12 the section marked "Clinical summary", it says:

13 "Severe Haemophilia A, factor VIII less than
14 1 per cent, chronic recurrent haemarthroses and significant
15 haemophiliac arthropathy."

16 Which we discussed:

17 "On Factor VIII concentrate home therapy since
18 1979/1980."

19 Then:

20 "HIV seroconversion. Last negative 28 November
21 1983. First positive 20 June 1984."

22 He received batch 0090 of the Factor VIII and the
23 number of bottles he received was 50.

24 Could we have a look at WIT0040576? This is
25 a test result confirming your father's HIV diagnosis.

1 I'm sure there was probably an earlier one but --

2 A. Sure.

3 Q. It's in relation to a sample taken in July 1987. So

4 when your father told you that he had HIV, how was he at

5 that time?

6 A. Quite matter of fact. He told me the result and he told

7 me what it meant as far as he understood it, you know,

8 and it was, "Right", you know, "So this is the

9 situation, these are the things that we need to do, the

10 precautions that we need to take, and now we just need

11 to get on with it. You can't tell anyone ever."

12 The main thing was the stress for secrecy. That

13 seemed to be the only thing that was stressing him out.

14 Q. People finding out?

15 A. Yes.

16 Q. When you say that he told you what it meant as far as he

17 understood it, do you remember what that was?

18 A. They spoke about the need for the family to be tested,

19 although the risk was low, that the highest risk would

20 be to my mum but that there would be a minuscule risk to

21 me because I used to make up his treatment and help with

22 things, and that he was going to move into the spare

23 room because he had frequent nose bleeds. He was going

24 to have to move. We needed to avoid blood contact, that

25 it was going to reduce his life, that this was the

1 progress of the disease but it was unknown how long that
2 process would be and it could be -- I have written in my
3 diary at the time that he told me that, you know, it
4 could be up to five years that he would have. That's
5 all I remember.

6 Q. So this must have been very difficult news for you to
7 take on board --

8 A. Yes.

9 Q. -- while you are at school. How did your mother react
10 to this?

11 A. She was upset and then stuck her head down and didn't
12 talk about it at all. My mum didn't -- wasn't much of
13 a talker, so she just...

14 Q. Hunkered down?

15 A. Yes.

16 Q. You say that your younger brothers weren't told at this
17 time?

18 A. No.

19 Q. So was anybody else told at that time?

20 A. Initially I don't believe so. Subsequently his sister
21 was told and my mum's -- one of my mum's sisters and
22 then gradually people in the family. But initially, no,
23 it was just my mum and I.

24 Q. Okay. So you have told us that your father had
25 obviously found out what he could about the virus and

1 conveyed that to you. In paragraph 8 of your statement,
2 which is at WIT004005] --

3 THE CHAIRMAN: Can you prepare for a break in a few minutes.

4 MS PATRICK: Are you okay to look at this?

5 A. Yes, absolutely.

6 Q. You tell us that your father was very pragmatic as you
7 have told us and he seemed to have a lot of information
8 about HIV. You say:

9 "My impression was that he and DrLudlam had had
10 a frank conversation about HIV."

11 Was that about that time --

12 A. Yes.

13 THE CHAIRMAN: Can I ask just one question about
14 paragraph 7?

15 A. Sure.

16 THE CHAIRMAN: There you talk about the family being tested.
17 Did any medical person speak to you about it or was it
18 just your father?

19 A. No, we went to ward 23. We had our bloods taken and
20 then we went away.

21 THE CHAIRMAN: With no one giving you a frank talk about it?

22 A. No, I did not have a frank talk until I was older.

23 THE CHAIRMAN: We will have a break at that point.

24 (10.28 am)

25 (Short break)

1 (10.48 am)

2 THE CHAIRMAN: Yes, Ms Patrick?

3 MS PATRICK: Frances, I wonder if we could return to
4 something which you touched on earlier, just before the
5 break, in relation to the testing that your family
6 underwent after your father was diagnosed with HIV.
7 Lord Penrose has referred you to paragraph 7 of your
8 statement where you tell us that you all attended the
9 haemophilia ward at Edinburgh Royal Infirmary very soon
10 after your father was diagnosed with HIV and you were
11 all tested for HIV. You don't know who initiated this
12 testing but you thought it was standard and it was
13 DrLudlam who initiated it but you say also it could
14 have been your father. "Fortunately we all tested
15 negative."

16 A. Yes.

17 Q. I wonder if you could, please, have a look at
18 WIT0040569. Which is a letter dated August 1985 from
19 DrLudlam to your father, saying that he has looked
20 through their records and he is pleased to confirm that
21 you are all negative for the HTLV-III virus. Then if we
22 look at WIT0040571, DrLudlam writes again
23 in September 1985 to your father saying he has looked up
24 the results of the HTLV-III studies:

25 "we undertook on your family ..."

1 And that you were all negative. At the end of that
2 letter he says:

3 "I much appreciate the talk we had on the telephone
4 last night."

5 The Inquiry is aware that there was a meeting of
6 people with haemophilia at Edinburgh Royal Infirmary
7 in December 1984, at which DrLudlam was present and
8 some other doctors, and I wondered if you knew if your
9 father had gone to that meeting.

10 A. I don't know.

11 Q. You don't know. So you have never heard any mention of
12 such a meeting?

13 A. Round about that time there were hospital visits and
14 meetings and telephone calls and I don't remember any
15 specifics about that.

16 Q. Okay. Thank you. In paragraph 13 of your statement you
17 tell us that there was a nurse called Billie who worked
18 with DrLudlam. Was that at that time that your father
19 was diagnosed with HIV or was that later? If you can't
20 remember, please say.

21 A. I don't remember at the time but it was -- it wasn't all
22 that long afterwards-- if it wasn't at the time, it
23 wasn't all that long afterwards, within the first year
24 or so, I think.

25 Q. She offered support and counselling?

1 A. Yes.

2 Q. Was that to all of you?

3 A. Well, she offered it to all of us through my dad. So,
4 yes -- and she said it was available to all of us but
5 she only spoke to my dad, I believe. So she didn't
6 speak to me or my mum individually.

7 Q. You tell us that your father refused that offer on
8 behalf of all of you?

9 A. Oh, yes, he didn't believe in counselling.

10 Q. So I take it that he had no counselling?

11 A. He had no -- well.

12 Q. At that time?

13 A. No, he had no counselling, yes, and my mum was of the
14 same opinion; she was a very private person, didn't want
15 to talk about things.

16 THE CHAIRMAN: What was your father's express attitude to
17 counselling?

18 A. He thought it was a waste of time and for people who
19 were weak and he used to refer to psychologists and
20 psychiatrists as "trick cyclists". He was one of those.

21 THE CHAIRMAN: It fits in with what you were telling us
22 about his general character.

23 A. Yes.

24 MS PATRICK: In paragraph 9 of your statement you tell us
25 that at the time of your father's diagnosis with HIV, he

1 was well. [REDACTED]

2 A. Yes.

3 Q. [REDACTED]

4 A. [REDACTED]

5 Q. [REDACTED]

6 A. [REDACTED]

7 [REDACTED]

8 [REDACTED]

9 [REDACTED]

10 Q. [REDACTED]

11 A. [REDACTED]

12 Q. He had his own business [REDACTED] and
13 employed staff?

14 A. Yes.

15 Q. How many staff did he employ?

16 A. It varied. [REDACTED]

17 [REDACTED]

18 [REDACTED] He had two shops in Edinburgh.

19 Q. So you would say he was successful in his business?

20 A. Yes, he was; he was.

21 Q. You touch then on what you have already told us, that he
22 was very private and didn't want you speaking to anybody
23 about his diagnosis and that your two younger brothers
24 didn't know, and you say it was a difficult time
25 emotionally?

1 A. Yes.

2 Q. How did your family life change after your father's
3 diagnosis with HIV?

4 A. From the time that he told me in that December, it was
5 almost like there was the beginning of a strange sort of
6 role reversal, because he was always very protective of
7 my mother. So there was a shifting in roles where he
8 and I were protecting my mum from the harsh reality of
9 life.

10 He carried on -- he carried on working, obviously,
11 and he moved into a different room, and often in the
12 evening he would call me through and we would talk [REDACTED]

13 [REDACTED]

14 [REDACTED]

15 [REDACTED]

16 [REDACTED]

17 about things.

18 So -- it was almost like I became my Dad's
19 counsellor, I was the person that he spoke to and made
20 plans with. So it changed the dynamic.

21 Q. You touch on that in paragraph 23 of your statement,
22 where you say:

23 "He needed someone to speak to and he spoke to me."

24 A. Yes.

25 Q. At that time you were 15 years old. You were doing well

1 at school?

2 A. Hm-mm.

3 Q. Before his diagnosis. But that changed?

4 A. Yes.

5 Q. You went from being top of the class to struggling
6 academically?

7 A. Yes.

8 Q. You say you had always enjoyed learning and you now felt
9 you were having to deal with all of this?

10 A. It was very difficult because I couldn't talk to anybody
11 about it. So I did not have -- I didn't know how to
12 support him. I didn't know what to do. So I had this
13 overwhelming feeling of responsibility but I didn't know
14 how to meet it. So -- and I had nobody to ask.

15 Q. So he was able to talk to you but you had nobody that
16 you could talk to?

17 A. Yes.

18 Q. Did your father seem to have any symptoms of HIV at the
19 time of his diagnosis with the virus?

20 A. Not at the time of diagnosis, no.

21 Q. You say in paragraph 12 of your statement that in about
22 1986 to 1987, that was when he began to become
23 noticeably unwell?

24 A. Hm-mm.

25 Q. In what way did you notice him start to become unwell?

1 A. He lost weight. His hair thinned. At some point he
2 became jaundiced but I think it was after that. He had
3 some abdominal swelling. He was tired. He would have
4 diarrhoea.

5 Q. We can have a look at a few of the medical records. If
6 we look firstly at WIT0040572. This is a discharge
7 summary from Edinburgh Royal Infirmary
8 dated September 1986. The principal diagnosis, as you
9 will see on the left-hand side, is severe Haemophilia A,
10 blood in urine and renal colic. He had had a three-day
11 history of blood in his urine and had developed
12 left-sided renal colic the day before being seen and
13 I think he had spent a night in the Royal Infirmary in
14 Glasgow?

15 A. That's right.

16 Q. I think the pain finally settled after he had been kept
17 in overnight there and passed some blood clots, but he
18 continued to have the blood in the urine, which is why
19 he came to Edinburgh Royal Infirmary. There your father
20 described a three-week history of feeling generally
21 unwell, malaise and tiredness. He had had intermittent
22 sweats but no real drenching night sweats. His weight
23 was steady and appetite good and systematic enquiry
24 revealed that he was having shortness of breath on
25 exertion whilst climbing stairs and hills?

1 A. Yes.

2 Q. There was no swollen lymph nodes on examination and he
3 was admitted to ward 23 for bed rest and treatment with
4 Factor VIII. He was then allowed home after two nights
5 in hospital.

6 If we turn to WIT0040573, we can see that just
7 over two weeks later your father was re-admitted to
8 hospital once again for two nights and this was on
9 3 October, with a recurrence of malaise and night
10 sweats. He also had some nausea and vomiting but no
11 diarrhoea. He had intermittent, mild dyspnoea and no
12 cough sputum or chest pain. Now there is palpable
13 cervical and axillary lymphadenopathy. It is noted at
14 the bottom:

15 "His symptoms settled over 48 hours and he was
16 discharged on 5 October. A provisional diagnosis of
17 AIDS-related complex has been made."

18 The plan was then that he would be re-admitted for
19 some further investigation.

20 Did your father tell you at that time that his
21 illness had progressed to AIDS?

22 A. Yes.

23 Q. Was another symptom that your father suffered, warts?

24 A. Yes. He had one on his foot for ages and ages and ages,
25 and I think he maybe had one on his hand but his foot

1 used to cause him pain. I think he went to chiropody
2 and freezing and whatnot.

3 Q. Okay. Could we turn to the treatment that your father
4 received. You mention in paragraph 6 that he was
5 treated with AZT, which was the only medication
6 available at that time?

7 A. Hm-mm.

8 Q. Could you, please, look at WIT0040577? This is
9 a letter from DrLudlam to your father, dated
10 1 October 1987 and headed "AZT". It says:

11 "You will know that AZT is now available for use.
12 It is possible that it might be of benefit to you and
13 I should therefore like to meet with you to consider the
14 possibility of you starting this anti-viral therapy."

15 And asking him to come to an appointment on
16 14 October to discuss this. Did your father discuss
17 this with you?

18 A. Yes.

19 Q. Yes. What was his view about treatment?

20 A. He absolutely wanted to try whatever was going.

21 Q. If we turn to the clinical notes about that meeting on
22 14 October, which we have actually looked at already,
23 WIT0040608, you will see at the top:

24 "Discussion about AZT with [your father] by
25 DrLudlam and myself."

1 The note-writer. As you say, your father is keen to
2 give it a try. There is the clinical summary, which we
3 have already looked at. If we scroll down, there is an
4 outline there of the symptoms that your father has been
5 suffering. In September 1986: malaise, sweats, weight
6 steady and apyrexia?

7 A. I think that says "apyrexia".

8 Q. Thank you. October 1986: drenching night sweats, PGL.
9 Autumn 1986 to summer of 1987: intermittent bouts of
10 malaise, sweats. June to July 1987: persistent
11 diarrhoea, sweats, malaise, some weight loss, not gross,
12 and exertional shortness of breath. July
13 to October 1987: continued malaise, night sweats,
14 occasional bouts of diarrhoea. You will see underneath
15 that it notes:

16 "Longstanding liver enzyme disturbances since 1983.
17 Fairly substantial alcohol intake."

18 Then there is a query there:

19 "Non-A non-B/alcohol."

20 So they are obviously looking at reasons for the
21 disturbed liver enzyme results.

22 A. Sure.

23 Q. Then going over the page, they list the three
24 indications that they see as being ones for the starting
25 of AZT. I'm not sure what's meant by the first one. Do

1 you?

2 A. AIDS-related complex?

3 Q. Yes, and the second one is his T4 count, progressively
4 declining.

5 As you will see from further down, on 21 October
6 your father started on AZT. It looks like, I think,
7 from that line that he is taking it four times a day?

8 A. Yes, could be, four-hourly.

9 Q. Then if you look at the entry for 28 October 1987, the
10 third line says he is getting a metallic taste in his
11 mouth from the AZT but no other side effects. Do you
12 know if he suffered any other side effects later on in
13 respects of his AZT treatment?

14 A. I'm not sure. It's hard to quantify what might have
15 been side effects and what might have been illness, but
16 I'm not aware of anything specifically being related to
17 that clearly.

18 Q. Okay, thank you. In June 1988 your father was
19 investigated for pneumonia. If you could, please, have
20 a look at WIT0040579. This is a letter to DrLudlam.
21 If we scroll down, you will see it's from NJ Douglas of
22 the department of respiratory medicine at the
23 City Hospital, telling DrLudlam that he saw your father
24 while DrLudlam was away. This is in June 1988. He
25 says that your father gave a story of six months

1 lethargy and ten days increasing dyspnoea exertion with
2 occasional bouts of breathlessness while at rest:

3 "He had no wheeze and no symptoms of an upper
4 respiratory tract infection in the last fortnight,
5 although he did have a heavy cold a month ago."

6 He had a dry cough. He was a lifelong non-smoker
7 with no previous chest troubles. He describes the
8 results of various tests including a normal chest x-ray.
9 Towards the bottom he says:

10 "These features show mild airways obstruction but
11 with no evidence to support pneumocystis pneumonia."

12 Which was obviously the concern at that point.

13 A. Sure.

14 Q. They were trying to treat this with an inhaled Beta 2
15 agonist and he is shown how to use this inhaler. When
16 he sees him again, your father tells him that he is
17 slightly better. So that seems to have helped at that
18 point?

19 A. Yes.

20 Q. I wonder if you could, please, look at WIT0040580.
21 This is still in June 1988 and I'm sorry, it's not so
22 clear at the top of the document. It's a letter to
23 Dr Parker from DrLudlam, which we will see when we
24 scroll on to the second page. He is writing to bring
25 Dr Parker up-to-date with your father's current

1 problems:

2 "As you know, he has been a little short of
3 breath with a dry cough for some time."

4 It mentions he has been seen by Neil Douglas:

5 "His chest x-rays have been virtually clear, except
6 for the possibility of a little shadowing at his left
7 base." His oxygen saturations are normal.

8 Neil Douglas is a little reluctant to undertake
9 bronchoscopy and biopsy but would do so if his clinical
10 condition progressed. DrLudlam then narrates the
11 problems that your father is having in relation to his
12 liver and that his LFTs are grossly deranged and various
13 other results, and on examination he has a large liver.
14 I think that you know that first-hand too?

15 A. Yes.

16 Q. Because you tell us at your father got you to feel his
17 enlarged liver and spleen?

18 A. [REDACTED]

19 [REDACTED] yes.

20 Q. [REDACTED]

21 A. [REDACTED]

22 [REDACTED]

23 [REDACTED]

24 Q. Niall Finlayson there is arranging an abdominal CT scan
25 and liver ultrasound with a view to a liver biopsy.

1 I think it's a recurring theme through the medical
2 records that liver biopsy was suggested to your father
3 but he was not keen at all to have one?

4 A. Yes, I remember that. He couldn't see what the benefit
5 to him was going to be and there was going to be a risk,
6 so he wasn't keen at all.

7 Q. Do you know if he had a liver biopsy?

8 A. He did but it was in his last 24 hours of life.

9 Q. Yes. Your father there is keen that the CT scan and
10 liver ultrasound be postponed because he has pressing
11 business commitments as his shop manager is going to be
12 away and he needs to cover the shop. So is it fair to
13 say that your father was having to spend more time away
14 from his business due to his symptoms of HIV?

15 A. Yes.

16 Q. Yes. It says at the bottom:

17 "The possible pathologies in his liver include
18 opportunistic infection, non-A non-B hepatitis and
19 lymphoma."

20 If we move on to the next page, ending 0581, we will
21 see he has an upper respiratory tract infection at
22 present and nasal swab has grown staph aureus. As he is
23 getting quite a number of nose bleeds, he has been given
24 a short course of antibiotics.

25 With regard to your father's liver function tests,

1 I wonder if you could have a look at WIT0040582. This
2 is a letter from Dr Finlayson, consultant physician from
3 the gastrointestinal and liver service at the Edinburgh
4 Royal Infirmary to DrLudlam, dated July 1988. He has
5 been seeing your father there in relation to his
6 abnormal liver function tests.

7 Under "History" he narrates that over the years your
8 father has been given much blood and many blood
9 products. He has had reactions to some of these but in
10 general has kept very well over the years. He has never
11 had jaundice but was apparently told by Dr Davies in the
12 mid-1970s that he had had a subclinical episode of
13 hepatitis, and I know from his records that since 1980
14 his plasma alanine amino transferase activity has been
15 increased. It refers to his infection with HIV. It
16 says:

17 "He himself remained very well until about six
18 months ago when he began to feel irregularly tired and
19 lethargic."

20 It refers to the problem with his cough and chest
21 and metallic taste in his mouth since he began taking
22 AZT.

23 He notes that his alcohol intake amounts to at most
24 two units of alcohol a day on average. He notes on
25 examination that your Dad didn't look generally unwell,

1 was mildly jaundiced. He didn't detect any
2 lymphadenopathy and he notes his further examinations.

3 If we go over to the next page, he states his
4 impression, which is on the third line, that:

5 He "does look to have chronic liver disease and
6 I would think it is likely that this is probably the
7 consequence of a chronic non-A non-B hepatitis viral
8 infection acquired from his blood product therapy.
9 However, there is also the possibility that he is
10 developing the AIDS syndrome, as suggested by his
11 respiratory illness, and in that case hepatic
12 involvement could also be present though, in most cases
13 of hepatic AIDS, other features of the AIDS syndrome are
14 much more prominent than is present here."

15 He raises the possibility that your father is
16 developing a lymphoma in relation to his HIV infection
17 and he is suggesting an ultrasound examination and a CT
18 scan, and then:

19 "If the ultrasound examination points strongly to
20 hepatic disease, then we should seriously consider
21 a liver biopsy."

22 So was your father aware at that point that the
23 doctors thought that he had non-A non-B hepatitis?

24 A. Yes.

25 Q. In fact he received treatment for this?

1 A. Yes, he did.

2 Q. You refer to that in paragraph 10 of your statement,
3 when you say that he had Interferon treatment for six
4 months some time between 1984 and 1987. In fact it
5 appears that this might have been in 1988 from the
6 medical records. You say you were still living at home
7 and you tell us that it made him feel quite ill and he
8 had flu-like symptoms. He was very tired and had
9 dreadful diarrhoea.

10 You tell us about your father's strong work ethic
11 and that if he could stand up he went to work. So he
12 continued to work through the treatment?

13 A. Yes.

14 Q. You say you do not know if the treatment was successful
15 but:

16 "... feel I would have known if it had
17 because it would have been a bit of good
18 news."

19 Which would presumably have been very welcome.

20 I wonder if you could have a look, please, at
21 WIT0040586. Once again apologies for the state of the
22 copy here. That is letter from DrLudlam to your
23 father's GP telling him:

24 "We are seeing your father fairly frequently."

25 This is in October 1988. That he is on antiviral

1 treatment. It says he thinks that he is likely to have
2 non-A non-B hepatitis and that the only way to make
3 a positive diagnosis would be a liver biopsy. I think
4 it reads:

5 "but in view of his severe haemophilia and slightly
6 prolonged prothrombin time, also his propensity to
7 allergic reactions to Factor VIII concentrate, both
8 I and Dr Finlayson feel that biopsy would not be
9 without hazard. Because of this, we have decided to
10 treat him for non-A non-B hepatitis with interferon
11 Alpha 2b. He is receiving this at a dose of 3 million
12 units 3 times weekly, subcutaneously. He is
13 giving this to himself."

14 So your father was basically injecting himself with
15 interferon three times a week?

16 A. Yes.

17 Q. "It is possible that he may be a little upset by the
18 treatment and develop flu-like symptoms but if these are
19 troublesome then we shall reduce the dose."

20 You have told us that they did indeed produce these
21 symptoms.

22 A. Yes.

23 Q. WIT0040588 tells us that unfortunately this treatment
24 has been unsuccessful. It's a letter from DrLudlam to
25 your father's GP, dated January 1989. He has been

1 reviewing your father because he had a bad head cold and
2 he notes in the second paragraph:

3 "He has been on a trial of subcutaneous interferon because of
4 presumed non-A non-B hepatitis which has caused
5 hepatosplenomagaly. Unfortunately he gained no improvement from
6 this and I have therefore discontinued it."

7 In paragraph 12 of your statement, you recall that
8 your father developed pneumocystis, which is specific to
9 HIV. Was this around the time that he was supposed to
10 be going on holiday with you all?

11 A. I wasn't going, it was my mum and my brothers, and
12 I think it was maybe Easter or that kind of time.

13 Q. I can show you the records about this. Your father
14 discussed, was it, a holiday to Spain?

15 A. Yes.

16 Q. Your father discussed this with the doctors. We can see
17 it at WIT0040634. This is at the bottom of this page.
18 It's clinical notes dated 2 June 1989, saying that your
19 father is very keen to go to Spain, to be with his
20 family, as he considers it may be his last holiday that
21 he will have with them. He realises that this curtails
22 his present investigations and he knows that he may have
23 other infections or medical problems but he is very keen
24 to go. You say in paragraph 12 that in fact he didn't
25 manage to go?

1 A. No, he did.

2 Q. Oh, he did manage to go?

3 A. He had sent them on ahead and he went and joined them

4 afterwards. I think that's --

5 Q. That's after he had pneumonia?

6 A. Yes, he was due to go the day or the day after he went

7 into hospital, and so they went on ahead. He didn't

8 tell them anything about it, how serious he was, how

9 seriously unwell he was, and then he joined them.

10 Q. Okay. Have a look at WIT0040697. This seems to be

11 the day after that clinical note, that your father is

12 admitted to hospital. You will see that the principal

13 diagnosis is severe Factor VIII and pneumocystis

14 pneumonia. Your father was admitted on 3 June and

15 discharged on 13 June.

16 It narrates his history and tells us at the bottom

17 of the first paragraph that AZT was discontinued

18 in May 1989 due to bone marrow suppression. So by this

19 time your father has stopped his AZT. It tells us about

20 increasing problems with exertional dyspnoea. This is

21 the middle of 1987. He had been reviewed by the chest

22 physicians in May who could not find any conclusive

23 evidence of chest disease. It then notes the findings

24 on admission. If we turn to the next page, which ends

25 0695. Sorry, it's a bit light, this copy. At the end

1 of the second paragraph:

2 "Bronchoscopy confirmed a diagnosis of pneumocystis
3 pneumonia."

4 Your father was treated with high doses of
5 intravenous Septrin, which was discontinued on 17 June,
6 following which he received a week's course of high dose
7 oral septrin. He was also transfused with two units of
8 red cells and he had undergone a full infection screen
9 to exclude bacterial, fungal or viral infections and
10 these proved negative.

11 Over the page we see his current medication there,
12 which includes Septrin, Flucloxacillin and it says:

13 "He will be commenced on a Pentamidinenebuliser as
14 a prophylaxis for the pneumocystis as soon as that
15 equipment becomes available."

16 So it was after then that your father went off to
17 Spain and joined his family?

18 A. Yes. I can't remember if I took him to the airport the
19 day he was discharged or the day after but --

20 Q. So he was quite a determined man?

21 A. He was a very determined man.

22 Q. Thank you. I think around that time were you at
23 university or were you at school?

24 A. I was at university.

25 Q. I think being June, it was exam time for you and we can

1 see from WIT0040591 one of the doctors provided you
2 with a letter in respect of your exams, saying that it
3 has been brought to his notice that you are presently
4 sitting exams and he feels it important that the exam
5 board should take into consideration the external
6 pressure you are under and referring to your father's
7 admission as a patient in the Royal Infirmary and
8 he hopes with this in mind that a compassionate attitude
9 will be taken to your exam results by the faculty?

10 A. Yes.

11 Q. How were you getting on at university at that point?

12 A. Badly.

13 Q. Do you think that the cause of it was dealing with your
14 father's --

15 A. Absolutely.

16 Q. So did this letter help at all?

17 A. Well, it made them aware of what was going on. I had
18 spoken to my tutor and said about the pressure that
19 I was under. I failed all four of those exams.

20 Q. Right. Yes. You tell us in paragraph 23 that you
21 really struggled at university and you scraped through
22 your first year and failed your second year twice. Your
23 father was obviously keen that you do well?

24 A. He was.

25 Q. You feel that you had quite a different experience from

1 other students at university due to your father's
2 illness and you say you didn't lead a normal student
3 life?

4 A. No.

5 Q. Did you come home a fair bit?

6 A. I came home a lot and I felt separate to my peers
7 because they were out having fun and partying and
8 drinking and I was just distraught, trying to deal with
9 this and my exams and studying.

10 Q. Your father's condition continued to deteriorate.
11 I wonder if you could have a look at WIT0040639, which
12 is the note of a fairly frank discussion that your
13 father has had with the haemophilia sister
14 in August 1989, where it's noted that your father has
15 expressed some wishes regarding his impending demise,
16 and he doesn't wish your mother to be approached on this
17 subject and he expresses concerns about the writing on
18 the death certificate and so reassurance was given to
19 him about that. So that was obviously a concern for
20 him?

21 A. Hm-mm.

22 Q. He is obviously looking out for your mother?

23 A. Very much.

24 Q. He gives his consent for them to tell any other patient
25 that enquires about him what is wrong. So that

1 coincides what you are telling us, that gradually he was
2 becoming more open?

3 A. Yes.

4 Q. Moving on to June 1990, I think your father had
5 a further admission to hospital, WIT0040597. I don't
6 think it was a very long admission, this, but he had
7 been having persistently bleeding gums for a week and
8 had had severe nausea and vomiting from the treatment
9 for this. He continued to have a temperature on the
10 ward and was given broad spectrum antibiotics, which
11 helped quickly and the following morning he felt very
12 well indeed and he was then discharged home. There is
13 a plan there to introduce him to a further antiviral
14 treatment.

15 In paragraph 18 of your statement you tell us about
16 the day that your father died. He woke up and had
17 a bleed in his tummy and he said to your mum that this
18 was it and was taken to hospital and found to be
19 bleeding internally, and an operation was performed but
20 the doctors were unable to stop the bleeding and he died
21 that same day?

22 A. Yes.

23 Q. Where were you at that time?

24 A. [REDACTED]

25 Q. [REDACTED] You tell us that your father wanted you to

1 stay in [REDACTED] and keep going with your exams at that
2 point?

3 A. I had one last shot at my exams. Normally if you fail
4 your exam a number of times, you get expelled from
5 university and that had happened. I had been through
6 the appeal process. I had one last shot at the exams
7 and they started on the Monday. My Dad died on the
8 Friday. So he knew about these exams and was keen for
9 me to take them.

10 Q. So he told your mother not to tell you but your brother
11 did telephone you and you were able to get to the
12 hospital.

13 A. Hm-mm.

14 Q. I wonder if you could look at WIT0040599, which is
15 a report of your father's death by DrLudlam to the
16 Registrar General, the vital statistics branch at
17 Ladywell House in Edinburgh, informing them of your
18 father's death and saying that:

19 "it has been reported to the Procurator Fiscal's
20 office because, amongst other reasons, he was anti-HIV
21 positive. The fact that he had AIDS was not recorded on
22 the death certificate and I write to give you this
23 information in strict confidence."

24 So your father's wishes in that respect were adhered
25 to. There is a reply to that letter confirming that

1 that information was treat as strictly confidential.

2 Could we look at WIT0040604? This is a letter
3 from DrLudlam to DrRizza, director at the
4 haemophiliacentre Churchill Hospital, Oxford
5 in October 1909, informing him of your father's death as
6 a result of intra-abdominal haemorrhage. It confirms
7 what you told us earlier, that your father did have
8 a liver biopsy. His wishes having been respected. But
9 that demonstrated features of non-A non-B hepatitis.
10 Could I refer you to WIT0040605? This is a positive
11 Hepatitis C virus test result on a sample taken on
12 5 January 1988, having been received in November 1991
13 and reported on 13 January 1992.

14 I think you discovered after your father died that
15 he had had Hepatitis C?

16 A. Yes.

17 Q. Okay. You tell us in paragraph 19 of your statement at
18 0058 that your father couldn't work as much in the last
19 few years of his life. So there was less income and
20 there were financial implications for you all due to his
21 illness. When did your father stop work?

22 A. Oh, the business was still going when he died. So
23 I don't know that he actually stopped --

24 Q. He reduced?

25 A. -- work. He reduced.

1 Q. You tell us in paragraph 22 that after he had been
2 diagnosed with HIV, he took out some life assurance. We
3 know he had some before and he managed to find some
4 policies that didn't exclude paying out if death was
5 related to HIV. You tell us that the Macfarlane Trust
6 gave the family £60,000. The amount of the award
7 depending on the number of dependents in the family?

8 A. Yes.

9 Q. And that this paid for the house.

10 A. I think the house was already paid for.

11 Q. Was it? Right. So how did you manage financially,
12 after your father's death?

13 A. He owned several shops, so we rented those out and that
14 £60,000 and money from insurance, so he had left enough
15 for my mum and my brother to be looked after.

16 Q. Right. Because your mother obviously didn't work?

17 A. She didn't work after I was born.

18 Q. No. You tell us that when your father died, she didn't
19 even know how to pay her gas bills. Your father had
20 obviously looked after everything?

21 A. My father did everything.

22 Q. How did your father's illness and death affect your
23 mother?

24 A. She was -- she was obviously -- she was devastated. She
25 didn't really have much of a life outside the house.

1 She had one friend that she would visit a couple of
2 times a year but my dad was her whole life, and she was
3 a smoker and a drinker and she drank and smoked
4 increasing amounts until it killed her.

5 Q. You say in paragraph 20 of your statement that after
6 your father died, your mother continued drinking and
7 became an alcoholic and as you say, she increased her
8 smoking habit. She drank vodka and coffee and didn't
9 eat and she eventually died in 2000, weighing only 5
10 stone?

11 A. Yes.

12 Q. How did your father's illness and death affect the elder
13 of your two brothers?

14 A. He didn't know about my dad's illness until a few months
15 before he died. It was in 1990 that he was told and
16 I remember I had to push my dad to tell him. He was 18
17 by that time and I could see that my dad was becoming
18 more and more unwell and I felt that it was important
19 that he had some warning. So he -- although dad had
20 been unwell, he wasn't hugely aware of it. It had been
21 very much downplayed. In our whole lives we were used
22 to him going in hospital. So he only had a short period
23 of time to get used to the idea before he died and he
24 became very angry. He was a teenager anyway.

25 Q. You say he was 19 years old when your father died?

1 A. I think he was 18.

2 Q. In paragraph 25. Don't worry.

3 A. [REDACTED]

4 [REDACTED]

5 [REDACTED]

6 [REDACTED]

7 [REDACTED]

8 [REDACTED]

9 I think he felt that he needed to be the man of the
10 family. Didn't know how to and was a bit resentful of
11 me because I seemed to know much more than he did. And
12 he comes from the same stock as my parents. He is not
13 a talker, so we have never really discussed how it
14 affected him because he doesn't want to talk about it
15 but his life became smaller.

16 He trained as [REDACTED]

17 [REDACTED]

18 [REDACTED]

19 [REDACTED]

20 [REDACTED]

21 [REDACTED]

22 [REDACTED]

23 [REDACTED] He had an

24 accident in his boss' car and he hurt his back and he

25 needed surgery for that. So he couldn't do [REDACTED]

1 [REDACTED] then. He hasn't worked since. [REDACTED]

2 [REDACTED] There is probably something else he
3 could do but I think he is emotionally damaged. It's
4 too big a thing to retrain. Whereas if my dad had been
5 around, he would have had more of a push, more support.

6 Q. Yes. You touch on that in your statement, that you were
7 obviously a very supportive part of your family during
8 your father's illness and you continued to be that way
9 after.

10 A. Yes.

11 Q. As you are aware, your younger brother provided
12 a statement to the Inquiry, and that is WIT0040537.

13 Starting at paragraph 4, he recalls that when he was
14 five years old, he was taken to the blood transfusion
15 centre for a blood test and he didn't know why he was
16 having a blood test at that time. When he was 18 or
17 19 years old, he discussed it with his mother and was
18 shocked to learn that the blood test was to determine
19 whether or not he had been infected with HIV. He
20 recalls that your father was often in hospital but he
21 was not aware of the reason for this. And for as long
22 as he can remember:

23 "My parents slept in separate beds."

24 He thought that that was normal because he slept in
25 a separate bedroom from you. So his logic as a child

1 was that boys and girls slept in different beds. He
2 remembers once when he had a friend round to the house,
3 he showed him round and told him where everyone slept
4 and his friend was amazed when he heard that your
5 parents slept in separate beds.

6 He recalls that your father could be an angry,
7 irritable man, who was occasionally very mean to him and
8 that your mother was the voice of reason. That your
9 father once threatened to throw out all his toys because
10 he hadn't cleaned his bedroom in the time allocated, and
11 he thinks that was when he was about seven.

12 He recalls that he was ten when your father died and
13 that you were away at university and, as you have
14 described yourself, your other brother seemed to be
15 a very angry person at this time and he continued to
16 live at home until he went to university, when he was
17 21.

18 He felt that your father's friends disappeared after
19 your father died and he felt angry at them for not
20 supporting your mother. When he was older he learned
21 that some of his friends had tried to support your
22 mother but your mother wasn't interested. As you have
23 already told us, your mother enjoyed being with her
24 family.

25 So basically, after your father died, it was this

1 brother who was living with your mother?

2 A. Yes.

3 Q. He was saying that your mother would do the washing and
4 ironing and he took over the gardening when your father
5 died, and then later did more of the housework when he
6 was 16 years old:

7 "My mother said to me that she was proud that she
8 had seen all her children grow up and that she could die
9 now. She had no appetite and was really frail."

10 He doesn't recall her drinking excessively while he
11 was at school. When he got home from school, she was
12 always interested in his day and was never drunk at that
13 time of the day. In the evenings she would have
14 a couple of glasses of wine and then went to bed and she
15 smoked a lot. He says that by the time he was 18 years
16 old, your mother was drinking more and she would get up
17 during the night and fall over and he would get up and
18 help her back to bed.

19 He says that when he was 20, your mother got up
20 during the night and fell and broke her hip and she was
21 taken to hospital, where she died three weeks later as
22 a result of liver failure. He then carried on living in
23 the family house for a year and then your brother bought
24 the family home and he moved in with his girlfriend and
25 completed university studies.

1 You have told us, as we have gone through this, the
2 impact of your father's illness on you. You have told
3 us in paragraph 24 of your statement that you have
4 received treatment for depression and, as you know, we
5 have received a report from your GP, which I would like
6 to refer you to, which is WIT0040699.

7 This confirms that your GP knows you very well,
8 having been your GP since the 1990s, and that over the
9 years you have been prone to anxiety and depression and
10 that you have had many discussions with your GP at these
11 times. That the role of your father's illness and your
12 mother's problems, which she gathers were related to
13 your father's illness, have always been very
14 significant.

15 She provides a brief summary of your attendances
16 in April 1997, January 1998, with low mood, stress
17 symptoms, anxiety and the treatment that you received in
18 respect of these symptoms.

19 At the end she says that throughout these years you
20 have had fluctuations in your moods, having some bad
21 spells related to ongoing family problems:

22 "Over the years she has demonstrated a very
23 resourceful personality, coping incredibly well [REDACTED]
24 [REDACTED] as well as dealing with her
25 family issues. I have no doubt that her father's

1 illness, and in turn the effects that this had on her
2 family, have had an immense role to play [REDACTED]

3 [REDACTED]
4 Is there anything else you would like to tell us
5 today about the effects of your father's illness and
6 subsequent death on you?

7 A. It's hard for me to imagine what my life would have been
8 like. [REDACTED]

9 [REDACTED] I think at the time, had
10 I been able to have some sort of support, it possibly
11 wouldn't have had quite such an ongoing effect. One of
12 the difficulties is -- and I was talking to someone
13 about this recently -- it might sound a bit odd but it's
14 bad enough to lose your parents but you get over that.

15 I think one of the difficult things is a sense of
16 shame, [REDACTED] and I know there is not real
17 shame but they are not neat, tidy acceptable deaths. It
18 subsequently means that I don't feel able to talk about
19 them. My dad had AIDS and my mum was an alcoholic.
20 It's not, you know, "My dad had a heart attack". It has
21 contributed to quite a private personality. This is --
22 this has been quite a difficult process for me because
23 I'm talking about things that I don't talk about. And
24 I have done the work, you know, I have had some
25 counselling myself, I don't share my parents' views on

1 counselling.

2 I have done the work and I have dealt with it, but
3 it's just utterly changed my life. It has affected how
4 I relate to people. It has no doubt affected my choice
5 of speciality, it has affected my relationships. It has
6 influenced my choices in -- whether or not to have
7 family. I don't have children. It was just too
8 difficult to think about, because my dad is
9 a haemophiliac, I'm a carrier. It was too difficult to
10 think about having a child but it was bad enough going
11 through it with my dad. With the possibility of going
12 through it with a son was just too hard. That makes me
13 sad.

14 Q. I appreciate how very difficult this has been for you.

15 I would like to thank you very much.

16 A. Sure.

17 Q. Thank you, sir.

18 THE CHAIRMAN: Content, gentlemen?

19 MR DI ROLLO: I don't wish to ask any questions.

20 MR ANDERSON: I have no questions, sir.

21 THE CHAIRMAN: Frances, thank you very much.

22 A. Thank you.

23 THE CHAIRMAN: If there is anything that you do think about
24 when you go away, just let us know. I don't want to see
25 your diaries for good reasons, but you know that we are

1 interested in precise dates and if you have thought of
2 anything that might help us pinpoint bits in the
3 history, for example, or brought back memories that you
4 might now find it easier to let us know about, we are
5 here and willing to listen. Thank you very much.

6 MR DI ROLLO: There is some matter that I would wish to
7 raise with you but the witness needn't be detained.

8 THE CHAIRMAN: Very well. Thank you very much.

9 (The witness withdrew)

10 THE CHAIRMAN: Yes, Mr Di Rollo?

11 MR DI ROLLO: The matter was just relating to the medical
12 records of Frances and the dates of when a test was
13 carried out and when he was informed of the outcome of
14 that test. It's not apparent from the medical records
15 that I have seen that the dates which are spoken to by
16 the witness correspond to dates in the medical records.
17 If we have the medical records put up on the screen, we
18 will see what the situation is.

19 If we go to page 28, I think that's an entry for the
20 1 July 1984, and there doesn't seem to be any -- that's
21 the most recent entry -- the first entry to look at and
22 if we go to --

23 THE CHAIRMAN: Sorry, I can't actually see that date.

24 I don't know that I have the right bit on the screen.

25 MR DI ROLLO: 1 July 1984.

1 THE CHAIRMAN: That's the date of the letter.

2 MR DI ROLLO: The date of the letter.

3 THE CHAIRMAN: So that's not necessarily helpful. What is
4 it we are looking for, the date of an attendance?

5 MR DI ROLLO: If we go to the next entry in the medical
6 records it is 19 August 1985.

7 THE CHAIRMAN: This entry relates to June, we see in the top
8 right-hand corner.

9 MR DI ROLLO: Yes, sorry.

10 THE CHAIRMAN: 20th.

11 MR DI ROLLO: We have June 1984 and the next sheet
12 apparently in the medical records is August 1985. Then
13 the next sheet after that is one that my learned friend
14 showed the witness, which is 28 August 1985.

15 It's apparent from that that at that point there
16 seems to have been -- well, we can see what
17 Professor Ludlam has written there. There is no entry
18 before that that I have been able to see in these
19 records, which mentions or deals with a test for HIV or
20 anything of that kind, in relation to the patient
21 himself. The first entry that we see was the one that
22 my learned friend did show, which I think is at page 37,
23 if I have that right.

24 If we go to page 37, which is July 1987, that seems
25 to be the first entry for a test for HIV. The witness

1 was quite clear on her dates in terms of how old she was
2 and she talked about that later on in her evidence, but
3 she says at paragraph 5:

4 "My father was told in 1984 that he had HIV.
5 I believe he knew he was being tested for HIV. I am not
6 sure how he was told that he had HIV but I do believe it
7 was DrLudlam who told him. I was 15 years of age at
8 the time when my father learned of his diagnosis and
9 informed me."

10 She does say that in her statement.

11 THE CHAIRMAN: She is very much more precise than that. She
12 told us that she had looked in her diary and the date
13 was 21 December 1984, when her father told her that he
14 was HIV positive. There is not much need to speculate
15 about that. I have to tell you that the lady told me
16 that her diaries are typical teenage diaries, and there
17 is no way on earth that anyone is going to get access to
18 them.

19 MR DI ROLLO: Of course not.

20 THE CHAIRMAN: There is no reason at all to doubt for one
21 second that the date is precisely right.

22 MR DI ROLLO: The question really is that it is not clear
23 what the circumstances are surrounding that information
24 being given. Obviously, it is not apparent from these
25 records as to how her father was tested or when he was

1 tested and how he was told.

2 THE CHAIRMAN: There is quite a lot of circumstantial
3 information, you know. We know that the UKHCDO agreed
4 around about June 1984 that DrTedder's test would be
5 applied at some stage when it became available. We know
6 from the Cheingsong-Popov article towards the end of the
7 year that 2,000 people had been tested by December 1984
8 by DrTedder and his colleagues. So you have
9 a framework, and within that framework we have this
10 witness giving a very precise date when her father told
11 her.

12 Do I really need to pin it down beyond that,
13 Mr Di Rollo, this case? There may be other cases where
14 there are other questions, but as far as this one is
15 concerned, the circumstantial evidence points fairly
16 clearly, it seems to me, to samples from Edinburgh
17 having been tested within that timeframe and to the
18 information about some test, not necessarily those
19 precise tests, but information about some test being
20 given to the deceased in time to let him tell his
21 daughter on 21 December 1984.

22 MR DI ROLLO: Well, I don't disagree that that's what the
23 evidence seems to point to and I suppose the question
24 really is --

25 THE CHAIRMAN: Where are the records, yes, I suppose is the

1 question.

2 MR DI ROLLO: Yes.

3 THE CHAIRMAN: I don't know the answer to that but what do
4 you suggest I do?

5 Professor James, who has looked at the records,
6 tells me that there are entries --

7 PROFESSOR JAMES: We saw them this morning. There are
8 entries in the clinical records saying one test was
9 negative, retrospectively, I think the end of 1983. It
10 is written in the clinical records.

11 MR DI ROLLO: I have seen that.

12 PROFESSOR JAMES: Exactly. That it was positive
13 for June 1984. You will have the date on which that
14 clinical record was written but it was at the end of
15 1984 or the beginning of 1985.

16 MR DI ROLLO: The other --

17 THE CHAIRMAN: I would expect Ms Patrick to have the dates
18 of those records to give you. I don't have hard copies
19 of them myself. I'm going to have to have them, for
20 a variety of reasons.

21 MR DI ROLLO: These records were only produced yesterday to
22 me, if I may say that.

23 THE CHAIRMAN: I'm not being critical of you in any way,
24 Mr Di Rollo, don't worry.

25 MR DI ROLLO: I know you are not; I'm just explaining the

1 situation, that I'm raising this matter as a query and
2 that's all. One thing --

3 THE CHAIRMAN: Let's specify the query. Let's get it, as it
4 were, into the notes formally, so that I know, because
5 I'm sure it's going to be a recurring theme. So what is
6 the query?

7 MR DI ROLLO: The query is where is the equivalent records
8 that we see at page 37? Where is the record of the test
9 that was carried out on Frances's father and the result
10 of that test?

11 THE CHAIRMAN: How do you think that question can be
12 answered? It's like, "Where have all the flowers gone,"
13 you know. There will be records missing, there will be
14 records that were never kept properly. We are talking
15 about human beings and the way that they keep records.
16 I would not like to account for every record that I have
17 ever had in my possession. So what's the point?

18 MR DI ROLLO: Maybe there wasn't any point.

19 THE CHAIRMAN: I'm asking because, if there is a point, it
20 has got to be yours, Mr di Rollo, and I have to know
21 what it is.

22 MR DI ROLLO: Obviously it is of interest because clearly
23 Frances's father was a patient, a member of the
24 Edinburgh cohort.

25 THE CHAIRMAN: That's now very clear.

1 MR DI ROLLO: Therefore, it is of interest to know whether
2 he did or did not attend the meeting in December and
3 what his response to that may have been. He may have
4 been one of the people that decided to come forward and
5 have a test.

6 THE CHAIRMAN: Too late. The meeting was Christmas.

7 MR DI ROLLO: So the question then is, if he was informed
8 before --

9 THE CHAIRMAN: Yes.

10 MR DI ROLLO: -- the meeting, that is being dealt with in
11 a different way from other patients, it would appear.

12 THE CHAIRMAN: Well, at the moment I wouldn't be able to
13 conclude that.

14 MR DI ROLLO: No, of course not.

15 THE CHAIRMAN: But I have to tell you that it doesn't seem
16 to me to be a surprise that different patients might
17 have been dealt with in different ways because the
18 clinician is bound to tailor his approach to the
19 receptivity of his patient and everyone wouldn't have
20 been treated in the same way, one hopes. So variability
21 doesn't seem to me to be a very important factor.

22 As far as this gentleman is concerned, I can't
23 imagine any circumstances in which I would be able to
24 say that the evidence we heard today was not entirely
25 reliable in every degree and that he, therefore, knew of

1 his HIV infection before the general meeting at
2 Christmas, whether he attended it or not, because he
3 must have known it before --

4 MR DI ROLLO: He may not have been invited to the meeting,
5 I don't know.

6 THE CHAIRMAN: You are not going to be able to ask him, but
7 we do know that by 21 December he was in a position to
8 tell Frances. So the chronology in his case is not
9 difficult. We also know from the look-back that there
10 was -- 1982, I think it was -- I'm in as disadvantaged
11 a position as you are in not being able to access
12 immediately the record, but there are two dates on the
13 letter, or the record. One shows when he last tested
14 negative and the other showed when the first stored
15 sample had a positive result on testing what are those
16 dates, Ms Patrick?

17 MS PATRICK: The last negative result was 28 November 1983
18 and this is found in WIT0040608. The first positive
19 was 20 June 1984.

20 THE CHAIRMAN: So, critically, we know the timeframe within
21 which his treatment transmitted HIV infection to him.
22 It's quite an important period in the wider context.
23 I can understand your interest in that, Mr Di Rollo,
24 very important period, and I expect to hear a lot more
25 about that period as time goes on. But in his case we

1 know a great deal about it: we know when the blood
2 samples changed from negative to positive within quite
3 a tight timeframe and then we know the date by which he
4 was informed.

5 In the nature of things, we can't find out how he
6 was informed, except by asking DrLudlam.

7 PROFESSOR JAMES: We also know the batch number.

8 THE CHAIRMAN: 0090.

9 PROFESSOR JAMES: Which is the Edinburgh cohort batch
10 number, I think.

11 THE CHAIRMAN: Yes, it is. So I'll help you any way I can,
12 Mr Di Rollo, but I really need to know more pre --

13 MR DI ROLLO: It's an obvious point to raise that the
14 records --

15 THE CHAIRMAN: What, that there are records missing? There
16 must be on your approach, but I don't know.

17 Sorry, yes, let's hear.

18 MS PATRICK: It may assist if I say that we did recover
19 quite extensive medical records in relation to this
20 patient, excerpts of which were taken out and obviously
21 put on court book. I don't think the information that
22 Mr Di Rollo is referring to, being the test result from
23 the sample in 1984 and notes of the communication of the
24 HIV result to the patient, at this stage that that
25 information wasn't there, but that's not to say that

1 actually it's not. So, if it would help, we can go back
2 to the records which we have in the office and have a
3 look.

4 THE CHAIRMAN: Go back and check again? I think you are
5 going to have a busy summer, if you do that, Ms Patrick.
6 But you have been through them already, haven't you?

7 MS PATRICK: They have been gone through.

8 MR DI ROLLO: Again, you have indicated that the only way we
9 will know the answer to that is to ask DrLudlam.
10 I don't know whether -- and I would like to know if that
11 is something which you, sir, regard as being a fruitful
12 exercise. If you don't regard that as a fruitful
13 exercise, then it won't happen.

14 THE CHAIRMAN: I think that there are questions that I would
15 like to see explored with Professor Ludlam. I have no
16 reason at the moment to believe that they won't be but
17 it seems to me, for example, that in the light of the
18 evidence we heard yesterday, there are questions about
19 the approach that was adopted to the testing of archived
20 samples of haemophilia patient' blood, plasma or
21 whatever it was they were storing. And at the moment
22 the evidence leaves unanswered some questions in my
23 mind. As I have indicated earlier, I have read the
24 records of the UKHCDO that indicate when they were
25 getting information about the prospective availability

1 of a test that could be used, about the fact that Gallo
2 made certain agents on an experimental basis but not for
3 clinical use, that there was a rather tightly controlled
4 opportunity as it were, to explore the position in this
5 country and the UKHCDO took a decision that samples
6 would be submitted to DrTedder. That, I think, is
7 clear in the early summer of 1984.

8 I know from the published results of that testing by
9 Cheingsong-Popov, by the end of the year, 2,000 samples
10 had been tested. What I don't know are what protocols
11 were used in relation to that process of testing.
12 I don't know what Scottish samples, in detail, went
13 there. I don't know precisely when reports came back
14 and I don't know precisely how Professor Ludlam
15 responded to that. This is all information that I would
16 like to have, if it's possible.

17 But human beings being human beings, Mr Di Rollo,
18 I don't at this moment expect to get precise answers to
19 all these questions. What I would hope would emerge
20 from it would be a sufficiently reliable picture to be
21 able to set out a sequence of events in a satisfactory
22 way that told all your clients and the wider community
23 what went on and how the discoveries were made that HIV
24 was in the population in Scotland in particular, and in
25 Britain more generally.

1 I hope that we will get there at the end of the day.
2 You must know I have been reading some correspondence,
3 some of which annoyed me greatly, challenging the work
4 that was being done by this Inquiry -- and I tell you
5 that now, not quite openly but prepared eventually to do
6 it openly -- challenging the work that has been done.
7 Every effort has been made here to get answers to the
8 questions so that those who have real concerns about
9 what happened can get an explanation. They may not like
10 it but to the best of my ability, I will be looking for
11 that explanation and this is an important part of it.

12 But I don't think there is any doubt that Ms Dunlop
13 is clearly aware of the need to try to answer the
14 questions if she can.

15 MS DUNLOP: Certainly, sir. I think exactly as Ms Patrick
16 has said, on the basis that these are extracts from the
17 medical records, there is now a question mark as to what
18 piece of paper, if any, underlay the communication on
19 21 December 1984, and we would feel happiest if we went
20 back and looked at the records and tried, if we could,
21 to answer that question, but I can't rule out that it
22 has been overlooked.

23 THE CHAIRMAN: Thank you very much.

24 As ever, I would prefer you, Mr Di Rollo, and the
25 other representatives and Ms Dunlop, to have a chat

1 about these things and see if you can solve them. If we
2 can get a sort of consensual approach to answering the
3 questions as best we can, I will have an easier job at
4 the end of the day and I don't shrink from telling you I
5 want an easier job if I can in some areas.

6 MR DI ROLLO: I was just simply this morning raising
7 something which I felt duty-bound to do so and I'm sure
8 as I understood it, at least at the beginning of the
9 remarks that you made, sir, you weren't giving me a row
10 and...

11 THE CHAIRMAN: I'm not. But you can take it that I will
12 need an awful lot more persuasion than I have seen so
13 far, if the idea is that Thompson should get access to
14 and funding from me to read every bit of paper that
15 exists in this area.

16 MR DI ROLLO: I wasn't referring to any correspondence of
17 any kind in relation to the enquiry that I was making at
18 this time.

19 THE CHAIRMAN: Let's see how we get on --

20 MR ANDERSON: May I make an enquiry?

21 THE CHAIRMAN: An enquiry? Crumbs.

22 MR ANDERSON: In relation to the matter that Mr Di Rollo has
23 raised, you made the point, a rather obvious one
24 perhaps, that one can simply ask Professor Ludlam about
25 this. I'm conscious, as are those instructing me, of

1 the terms of the restriction order but it would seem to
2 me sensible that those instructing me might ask
3 Professor Ludlam about this very matter so that he would
4 be in a position or better prepared to perhaps answer
5 it, because if it's a matter that Mr Di Rollo wishes to
6 follow up, then it may be of assistance if
7 Professor Ludlam --

8 THE CHAIRMAN: I was thinking of questions in the generality
9 rather than the particular. But what do you say to
10 that? We have now got very clear evidence from Frances,
11 and I'm very anxious, Mr Anderson not to allow any
12 aspect of this Inquiry to do what I would describe as,
13 degenerate into a case study of particular cases.

14 MR ANDERSON: Of course.

15 THE CHAIRMAN: I would have thought at the moment, although
16 things may change, it was enough for Professor Ludlam to
17 know that a generic question had arisen about the
18 approach to and timing of testing.

19 MR ANDERSON: I think he is certainly aware of this.

20 THE CHAIRMAN: I think he must be aware of that.

21 MR ANDERSON: I simply was seeking guidance because of the
22 terms of the restriction order.

23 THE CHAIRMAN: You have a date that you can put to him.
24 There is a date that we now understand was the date by
25 which disclosure had taken place. That was a bit of

1 information that I would have thought you might give
2 him, but I don't want him to be told about the
3 particular case at this stage.

4 MR ANDERSON: We will do that. Within those parameters.

5 THE CHAIRMAN: Thank you very much. You have given me
6 a chance to talk more than I have been able to talk for
7 ages.

8 (12.24 pm)

9 (The short adjournment)

10 (1.30 pm)

11 DAVID

12 Questions by MS PATRICK

13 THE CHAIRMAN: Yes?

14 MS PATRICK: Thank you. This afternoon we have David.

15 I would like to start by introducing you to
16 everybody in the room just so you know who is here
17 today. Lord Penrose and seated next to him is
18 Professor James, the medical adviser to the Inquiry.
19 You know Margaret, who is sitting next to you, the
20 Inquiry witness liaison manager. Along the front row we
21 have, closest to you, the two stenographers, who are
22 noting what is said this afternoon and that will form
23 the basis of the transcript which I know you are aware
24 of --

25 A. Yes.

1 Q. -- of the hearing. Seated next to them is Maria McCann,
2 who is the secretary to the Inquiry and seated next to
3 her is Keith Fleming, who is in charge of documents this
4 afternoon. And he will be displaying the documents that
5 I refer you to on the screen in front of you.

6 A. Okay.

7 Q. Next to me is Laura Dunlop, the senior counsel to the
8 Inquiry, and seated behind her is Yasmin Shepherd, the
9 paralegal who has been assisting on this topic.

10 Along the front and behind them we have the lawyers
11 for the parties interested in this Inquiry. We have
12 firstly, closest to us, the patients, relatives and the
13 Haemophilia Society representatives. In the middle we
14 have the lawyers for the health boards and the Blood
15 Transfusion Service and closest to you we have the
16 lawyers for the Scottish Government.

17 You helpfully provided some while ago the Inquiry
18 with a witness statement.

19 A. Yes.

20 Q. Yes. I hope that you have a hard copy of that in front
21 of you but the file reference for that is WIT0040007.
22 In paragraph 1 you tell us that you are presently
23 44 years old?

24 A. That's correct.

25 Q. Is that still the case?

1 A. Yes.

2 Q. It is. You are married and have a daughter?

3 A. Yes.

4 Q. What is your occupation?

5 A. I'm currently unemployed.

6 Q. Right. And before that?

7 A. Prior to that I was a [REDACTED].

8 Q. What did that work involve?

9 A. That was really as a [REDACTED] within the

10 [REDACTED] sector.

11 Q. Right. Thank you.

12 In paragraph 2 you tell us that you have

13 Haemophilia B and that you acquired both HIV and

14 Hepatitis C from your treatment for that haemophilia?

15 A. Yes.

16 Q. In paragraph 3 you tell us that you were diagnosed with

17 Haemophilia B in 1969, when you were three years old?

18 A. Yes, I believe that's the first time my parents were

19 informed of it.

20 Q. Was there a family history of haemophilia?

21 A. Yes, there is.

22 Q. There is. You tell us there you have a 13 per cent

23 deficiency in your clotting factor?

24 A. That's correct.

25 Q. Has that varied a bit over the years?

1 A. I'm not aware that it has, no.

2 Q. Right. You say --

3 THE CHAIRMAN: I wonder, can we just pause. The 13 per cent
4 deficiency doesn't sound quite right to me. Is it
5 13 per cent of the normal level you have or is it
6 87 per cent of the normal?

7 A. I believe it's 87 per cent of the normal. I'm
8 classified as a moderate.

9 MS PATRICK: Sorry, that is my fault, sir.

10 THE CHAIRMAN: Not at all. It just didn't read quite right,
11 the way it was put.

12 MS PATRICK: So the level of Factor IX that you have is
13 13 per cent?

14 A. Yes.

15 Q. Thank you. You have said that that would classify your
16 haemophilia as moderate?

17 A. Yes.

18 Q. That's what has been told to you by the doctors, is it?

19 A. That's correct.

20 Q. As you are aware, the Inquiry has recovered your medical
21 records and excerpts of these have been lodged as
22 productions. Have you seen these productions?

23 A. I have, yes.

24 Q. You have. I wonder if I could refer you firstly to
25 WIT0040442, which is a letter about your initial

1 diagnosis with haemophilia. It's dated August 1970 and
2 if you scroll down to the bottom, you will see that it's
3 from RW Payne, Consultant Haematologist, at the
4 Victoria Infirmary to Professor Douglas at
5 Glasgow Royal Infirmary. It records that you were
6 recently referred to the blood clinic with a history
7 that in 1969 you bled for four days following a dental
8 extraction and also in June 1970 you had bled for more
9 than 24 hours following a small bite on your tongue.
10 It's noted there that you have five cousins who
11 apparently all have been diagnosed as suffering from
12 Christmas Disease, as it's also known.

13 It says in the third paragraph that:

14 "The Haematology department at
15 Glasgow Royal Infirmary kindly performed a Factor IX
16 assay on [you] on 4th of August 1970, the result of which
17 was reported as 11% average normal."

18 It asks that you be registered as suffering from
19 Christmas Disease and a haemophilia card issued so that
20 it could be passed to your parents.

21 So initially as a child you were treated at
22 Yorkhill Hospital?

23 A. Yes, that's correct.

24 Q. You can't remember the name of the doctor who was in
25 charge of your care as a child?

1 A. No, any time when I had to go up I would normally be
2 admitted through Accident & Emergency.

3 Q. Right and then treated where?

4 A. And then treated on the ward.

5 Q. And what ward was that?

6 A. I can't remember which ward number it was.

7 Q. Right. What type of ward was it?

8 A. Just a general --

9 Q. General?

10 A. Yes.

11 Q. You say in paragraph 4 that you were given your first
12 treatment when you were diagnosed with haemophilia and
13 you remember being in hospital when you were three or
14 four years old having fallen, but you are not sure about
15 the treatment you received. I wonder if you could look
16 at WIT0040443, which is a letter dated
17 12 October 1970, and is about an admission for a week in
18 hospital as a result of a bleed. How old would you have
19 been at this age?

20 A. Four.

21 Q. Four, okay. You will see from about the second line
22 that you were admitted with bleeding into your forehead
23 and around the eyes and after admission it was found
24 that in addition to the bruising around the face, you
25 had a bleed in the left knee and in an effort to prevent

1 this getting any worse, you were given three units of
2 fresh-frozen plasma in a rapid intravenous injection.

3 So you say you are not sure what treatment you
4 received as a child in your early years?

5 A. Yes.

6 Q. But that you do remember when you were about seven or
7 eight years old in about 1976 or 1977, the treatment for
8 your bleeds became easier and took less time and so you
9 think that may be when you first received Factor IX?

10 A. I definitely have the recollection that it did become
11 easier over time. Initially it did seem to be quite an
12 elongated process in getting the treatment into you and
13 that seemed to improve.

14 Q. How often did you need treatment for your haemophilia?

15 A. Only as required.

16 Q. How often would you say that was?

17 A. When I was younger, maybe once a year, due to accidents.

18 Q. Yes. What sort of things would trigger a bleed:
19 accidents mainly?

20 A. Accidents or the only other time I would need it is
21 cover if there was a dental extraction.

22 Q. And all your treatment at that stage was provided in the
23 hospital?

24 A. Yes.

25 Q. I think if we look at WIT0040447, this is notes from

1 an admission and as we can see from the bottom, you are
2 eight years old at this time, and the date is not that
3 clear but it looks like 1976, so does that tally?

4 A. Yes, I would certainly be eight years old.

5 Q. It shows us here that you had bumped your left knee and
6 it had become swollen and stiff and you are given two
7 units of fresh-frozen plasma. You will see down the
8 side the instructions, and I think initially you are
9 given the fresh-frozen plasma and then your treatment
10 consists of staying in bed. Then half way down the
11 page, "continue bed rest" and further down the page you
12 see "physiotherapy", and you are allowed up and in
13 a wheelchair?

14 A. Yes.

15 THE CHAIRMAN: Ms Patrick, which hospital is this?

16 MS PATRICK: The Royal Hospital for Sick Children.

17 THE CHAIRMAN: Yorkhill. I think it was the Victoria in the
18 last --

19 MS PATRICK: It was the Victoria, I didn't go into that.

20 There seemed to be a bit of confusion --

21 THE CHAIRMAN: We are back to Yorkhill.

22 MS PATRICK: We are back to Yorkhill.

23 THE CHAIRMAN: That's fine, yes. Your recollection is that
24 it was normally Yorkhill that you went to.

25 A. That's right.

1 MS PATRICK: If we go over the page, we can see in the first
2 entry in the left-hand column that you are continuing
3 physiotherapy. It seems to be a feature that you are
4 quite uncomplaining when you are in there:

5 "No complaints" seems to feature quite a lot and you
6 are still remaining in the wheelchair and then in the
7 right-hand column we see that later on you are given
8 a night splint. What was that like?

9 A. The night splint was really just to immobilise the joint
10 that you didn't cause any damage to it by twisting
11 during the night.

12 Q. Right.

13 A. It was quite uncomfortable but you just accepted the
14 advice that that's what's needed.

15 Q. Also hydrotherapy is mentioned there. How did you find
16 it as a child, being in hospital?

17 A. You were aware that it wasn't the normal. If a child
18 falls over and your friend falls over, bumps their knee,
19 whatever, they don't have to go to hospital. So you do
20 get to understand that you are different in a way.

21 Q. Was the hospital far from your home?

22 A. It was the other side of the city, of Glasgow.

23 Q. Right. Were your parents able to stay there with you,
24 or did you stay there on your own?

25 A. No, you stayed there on your own.

1 Q. But did you get to know the staff on the ward?

2 A. Usually, when I was there, I would probably be in there
3 for about a week at a time. So you did. You got to
4 know the nurses.

5 Q. So when treatment with Factor IX concentrate started,
6 you say that you were aware that your treatment became
7 easier and did that mean that your visits to the
8 hospital became less frequent?

9 A. No, it just meant the treatment -- in terms of
10 delivering the treatment -- was quick and it also seemed
11 to be effective more quickly.

12 Q. So did you spend less time in the hospital?

13 A. Yes.

14 Q. You tell us in paragraph 5 of your statement,
15 WIT0040008, about how having haemophilia affected your
16 childhood. You say that you were wary of contact
17 sports. You would have liked to have played rugby but
18 you weren't able to do that. You did play football but
19 sometimes picked up injuries from doing so?

20 A. Yes.

21 Q. And needed treatment. And you couldn't do the usual
22 rough and tumble activities which boys usually do?

23 A. That's correct.

24 Q. I think if we have a look at WIT0040451, these are
25 further notes of The Royal Hospital for Sick Children.

1 If we scroll down to the bottom, we can see you are 13
2 and you have a bleed of the right knee, which you have
3 received while playing football. So you are admitted to
4 hospital and received treatment -- you can see down the
5 right-hand side -- with Factor IX and a splint again,
6 x-rays required, bed rest continues. And if you scroll
7 over the page, I think you have had a Thomas splint on?

8 A. Yes, that was a bad one that I got then. I had a bad
9 injury to my knee playing football and my knee was in
10 a splint for -- I think it was two weeks, to straighten
11 my leg at that point, and then from there I was in
12 a cast for six weeks and then a walking support for
13 a further eight weeks and then physiotherapy after that.

14 Q. Was that the end of your football career?

15 A. Yes.

16 Q. Yes.

17 A. I did play football after that but certainly nothing
18 competitive.

19 Q. You took it a bit more gently?

20 A. Absolutely.

21 Q. You say in paragraph 5, going back to your statement,
22 that you didn't miss a great deal of school, although
23 you had one spell. Is this the spell in relation to the
24 injury?

25 A. Yes, it was.

1 Q. When you missed about three months of school due to the
2 bleed to your knee?

3 A. Yes, that's right.

4 Q. Was your school work affected by your treatment for
5 haemophilia?

6 A. The school were very good. When I returned home, they
7 organised some of the teachers to come to my home and
8 I got some tutoring that way and also homework was sent
9 to me, but certainly I didn't get any school work when
10 I was in hospital.

11 Q. So do you feel it affected your qualifications by the
12 time you left school?

13 A. No, I wouldn't say it did.

14 Q. According to the medical records, the reference being
15 WIT0040454, your care was transferred from The Royal
16 Hospital for Sick Children to Dr Forbes at
17 Glasgow Royal Infirmary --

18 A. Yes.

19 Q. -- in 1981. So that would have been when you were about
20 15 years old?

21 A. I would have been 14 or 15 at the time.

22 Q. Does that sound about right?

23 A. Yes, that's right. My understanding was that patients
24 remained at Yorkhill until about that age and then
25 transferred to Glasgow Royal.

1 Q. Yes. You will see on the screen in front of you this is
2 the referral letter -- could you scroll down, please? --
3 from Dr Willoughby, Consultant Haematologist. Does that
4 name ring a bell to you?

5 A. I knew the name. I can't recall ever having met
6 Dr Willoughby.

7 Q. It records that you have been attending intermittently
8 for a number of years but you are now of an age when
9 follow-up by Dr Forbes' department would be more
10 appropriate. He records your Factor IX assays giving
11 an 11 per cent level and he refers to your admissions to
12 hospital as a result of your haemophilia in the second
13 paragraph. And as you say, in the earlier stages of
14 your childhood there is maybe about one a year or one
15 every two years.

16 It notes that Mr Connor of the Orthopaedic
17 Department at RHSC has also been involved with your care
18 since November 1979, and that seems to be in relation to
19 this injury, football injury --

20 A. Yes.

21 Q. -- to your right knee. You also seem to have been given
22 some exercises to do as well?

23 A. Yes, that's right. I received physiotherapy at the
24 point where the injury had settled down sufficiently to
25 cope with that.

1 THE CHAIRMAN: You said you didn't play football
2 competitively after this.

3 A. No.

4 THE CHAIRMAN: What were you doing when you got the injury?

5 A. It was attending a Boys' Brigade event, playing
6 football.

7 THE CHAIRMAN: Oh, dear, yes. I keep sharing personal
8 experiences with everybody. You see, I was in the
9 Boys' Brigade until I was about 26. I can well
10 understand how you would come by an injury if you were
11 playing in that context. I was a Boy until I was 26.

12 MS PATRICK: I wonder if we could now look, please, at
13 paragraph 6 of your statement, where you tell us in
14 paragraph 6 that when you were about 18 years old in
15 about 1984, you started home treatment with Factor IX.
16 Medical records suggest this might have been July 1982.
17 Could that be right?

18 A. Yes, given the passage of time --

19 Q. It is quite understandable. It's a fair time back.
20 Could I refer you, please, to WIT0040456? This is
21 a letter dated 15 July 1982 from GD Lowe, senior
22 registrar at that time, to your GP, saying that:
23 "...we have now started [you] on home treatment with
24 Factor 9 concentrate, which we will issue from the unit
25 at regular intervals."

1 It explains you have been trained to perform
2 venepuncture, to reconstitute the concentrate, which is
3 kept in the refrigerator, and you have been told to
4 treat yourself at the first sign of a bleed. You are at
5 that stage still having physiotherapy for your knee and
6 you have been instructed to give yourself a regular weekly
7 dose before the physiotherapy?

8 A. That's correct.

9 Q. So at that point that you start the treatment
10 in July 1982, you are treating yourself as required for
11 a bleed?

12 A. Yes.

13 Q. Other than this treatment in respect of your
14 physiotherapy appointments? How long did the
15 physiotherapy last? Can you remember?

16 A. My recollection is it lasted probably three months.

17 Q. Three months, okay.

18 Going back to your statement in paragraph 6, you
19 tell us in the second sentence that you were taught how
20 to administer the treatment yourself, as we have seen,
21 and you took Factor IX weekly. So you may have taken
22 the Factor IX weekly for these physiotherapy
23 appointments and there may have been a break, and you
24 just took treatment as required?

25 A. I had a period where I had ongoing problems with my

1 knees and I required the treatment to keep it under
2 control.

3 Q. Yes. You refer to that in that paragraph and say that
4 that home treatment lasted for about a year and a half
5 and then stopped:

6 "As I didn't need it any more."

7 A. Yes.

8 Q. I would like to refer you to the records about this.
9 WIT0040457. This is a letter dated June 1983. Once
10 again from G Lowe, senior registrar, to your GP. It
11 states that you were reviewed last summer, that you had
12 marked synovitis on both knees and you were commenced on
13 two vials of Factor IX concentrate as home treatment
14 given by yourself weekly.

15 So that suggests that in the summer of 1982 you
16 started taking weekly home treatment in respect of your
17 knee problems?

18 A. Yes.

19 Q. It records that your response to this was fairly good
20 and there has been little pain or stiffness in your
21 knees since and there have been no problems with your
22 home treatment. You are examined and there are good
23 movements in your knees but still some evidence of mild
24 synovitis, especially in the right.

25 At this stage you are about to sit five higher exams

1 and you are going to wait and see the outcome of job
2 applications before deciding whether to go back to
3 school for a sixth year?

4 A. Yes.

5 Q. If you could scroll down to the bottom, it notes at the
6 very bottom that your serum transaminases are raised:

7 "which we commonly found in haemophiliacs on regular
8 treatment and these again will be repeated when we see
9 him next at the clinic."

10 You can see there there is a handwritten note:

11 "? non A non B hepatitis."

12 A. Yes.

13 Q. That's something that we are going to come on to later
14 on.

15 A. Okay.

16 Q. Had you heard of non-A non-B hepatitis at that time?

17 A. No.

18 Q. Do you remember these blood test results ever being
19 mentioned to you?

20 A. I have no recollection of that.

21 Q. You say in paragraph 6 of your statement, which we have
22 referred to, that you thought that this treatment for
23 your knees lasted about a year and a half. The medical
24 records suggest that it was a bit longer than that and
25 that it in fact lasted about three years, that

1 treatment. I would like to refer to you WIT0040464.
2 Could I refer you to the bottom of that, to the notes
3 dated 8 November 1985. It records:

4 "Well. No longer using prophylactic fIX - none
5 for 3 - 4/12 [*three to four months*]."

6 So that suggests that the treatment stopped in
7 about July or August 1985?

8 A. Yes, it was fine, there was no necessity for it. The
9 problems that I was having with my knees had settled
10 down and I didn't -- there were no other complications
11 as a result of the haemophilia. So I didn't feel the
12 need for the home treatment.

13 Q. That is noted there:

14 "Knees have been fine. No bleeds. No other joint
15 problems."

16 We are actually going to come back to this entry but
17 I wonder if I could refer you to the treatment sheets
18 for this treatment that we have been discussing, which
19 are at WIT0040524. They go on to WIT0040527. But
20 if we could have a look at the first page, WIT0040524...

21 Could we enlarge it a bit please?

22 These start initially in October 1981 and show
23 treatment, all of it being treatment with DEFIX. The
24 top shows treatments in response to actual problems,
25 actual bleeds, and then we also see the treatment that

1 you have received before your physio. The prophylactic
2 treatment that we have been talking about as "home
3 treatment" starts on 19 July 1982 and it looks like the
4 treatment is happening every week, occasionally every
5 two weeks. We can see there is a jump of two weeks
6 between 10 August and 24 August.

7 If we move on to the next page, the record continues
8 following on from the page before, which finished on
9 16 December 1982. This one starts at 22 December 1982.
10 Whose writing is this?

11 A. It must be the hospital. It's certainly not mine.

12 Q. If we scroll down, it shows the treatment continuing
13 through 1983?

14 A. What you did do, when you were on home treatments, the
15 hospital provided you with a record book. You recorded
16 the dates that you administered the treatment and the
17 serial numbers on the bottles that were used.

18 Q. Right. So did you do that every time you gave yourself
19 treatment?

20 A. Yes.

21 Q. What happened to that record?

22 A. You submitted it to the hospital.

23 Q. How often did you submit the records to the hospital?

24 A. It was each time I was picking up a new batch of
25 treatment.

1 Q. Was it a swap?

2 A. Yes, I would submit the records and then get another --

3 I can't remember how many months' time at a time I was

4 being given.

5 Q. Right. So you personally noted --

6 A. Yes.

7 Q. -- the number of every treatment that you got but you

8 don't have copies of that --

9 A. No.

10 Q. That went back to the hospital?

11 A. No.

12 Q. If we move down the bottom, we will see the last

13 treatment on that page is 3 September 1983, and if we

14 move over to the next page, ending 0526, it carries on

15 to the end of 1983 and the beginning of 1984, up to

16 8 April 1984. Then there is a different entry at the

17 bottom there, which appears to be in different

18 handwriting:

19 "Last issued 30 vials fIX, DEFIX

20 (non-heat-treated)."

21 There is a date, 10 December 1984, batch number,

22 "0540900". Does that entry mean anything to you?

23 A. No, it's not my writing.

24 Q. No.

25 A. I think I may have had some home treatment to keep at

1 home in the event of a bleed at that point. It would
2 have been the case that I would give myself an initial
3 treatment, and if it wasn't settling down to then
4 contact the hospital.

5 Q. Right. So that would have been in addition to the
6 prophylactic treatment?

7 A. Again, it would just be as required.

8 Q. Right. But the treatment you received from the hospital
9 was the same each time, was it?

10 A. Yes.

11 Q. You were able to use what you were given, either
12 prophylactically or as required for a bleed?

13 A. Yes, I do recall having some that I would keep at home,
14 that if I had a bleed -- because it is one of these that
15 the quicker you treat it, the quicker it responds.

16 Q. But were you not keeping it all at home?

17 A. No, it was the case that you would administer an initial
18 treatment and if it wasn't settling down quickly, then
19 to contact the hospital to get a proper diagnosis.

20 Q. Right. So during this period you did go into hospital,
21 you think?

22 A. I was certainly attending for the regular reviews and if
23 I had had a bleed, I would have attended the hospital.

24 Q. Right, okay. So there seems to be a gap because we get
25 to 8 April 1984, then there is this entry dated

1 10 December 1984 and then if we go over the page to
2 0527, once again there is more prophylactic treatment
3 with DEFIX from 11 December through to 8 June 1985. And
4 that seems to tally with the previous record I referred
5 you to, which suggested that was when you stopped your
6 prophylactic treatment, because things had got better
7 for your knee?

8 A. Yes.

9 Q. Could you bear with me a minute?

10 A. Okay. (Pause)

11 Q. We are just trying to work out what this might be
12 a record of because it's obviously not the treatment
13 that you gave yourself because you kept that in your own
14 handwriting and this isn't it?

15 A. No, that's not my writing.

16 Q. So this is recording dates that you are having
17 prophylactic treatment and the type of blood product and
18 the units.

19 A. I certainly wasn't attending hospital on a weekly basis.

20 Q. No. So do you have any idea what this is a record of?

21 A. I can only assume it's a copy of my records of the home
22 treatment.

23 Q. Right. Could it be the treatment that was given out to
24 you?

25 A. It may well be, as -- I don't know, I haven't seen these

1 records previously.

2 Q. No, I appreciate that.

3 THE CHAIRMAN: Could we look back to the previous sheet.

4 I think I'm losing the chronological chain here just

5 a little myself.

6 MS PATRICK: Yes.

7 THE CHAIRMAN: So it goes right down, as we see,

8 to April 1984 and then there is an entry dated

9 10 December 1984. Does a break at that time mean

10 anything to you?

11 A. No, I can't recall ever having stopped home treatment

12 and then restarted. My recollection is I continued with

13 it until the point that I felt it was no longer

14 necessary.

15 THE CHAIRMAN: Did you go on keeping your own records and

16 handing them in?

17 A. I kept my records for as long as I was administering

18 home treatment, yes.

19 THE CHAIRMAN: You don't have an answer for the break? No?

20 Sorry, that was a question to Ms Patrick for the

21 notes, not to you.

22 MS PATRICK: Sorry, just to follow this through a wee bit

23 further, you collected your treatment from the hospital?

24 A. Yes.

25 Q. Where did you collect it from?

1 A. The Haemophilia Unit at Glasgow Royal.

2 Q. How often did you do that?

3 A. As I say, I can't recall. I know I was attending
4 certainly every six months. So prior to me attending
5 they would order the next batch of home treatment for me
6 that I collected as part of the review.

7 Q. How did you store what was given?

8 A. In the fridge.

9 Q. In the fridge?

10 A. Yes.

11 Q. So would you have received six months' supply at one
12 time or is that quite a lot?

13 A. I can't recall exactly how many months I was given at
14 a time. I do recall the reviews were six-monthly.

15 Q. Right. But you can't remember if that tallies with when
16 you picked up the treatment?

17 A. If I have any other need to attend the hospital, it
18 would suggest I was given six months at a time.

19 Q. Yes, okay. Thank you. I think we will leave that
20 particular point there.

21 A. Okay.

22 Q. Thank you. If could we turn to paragraph 7 of your
23 statement, you tell us that with regard to the treatment
24 you received for your haemophilia, nothing was ever
25 discussed with you regarding the benefits and risks of

1 this treatment. You were not warned of any risk of
2 infection as a result of the treatment you received
3 except once in about 1984, when you were 18 years old.
4 And you say at this time you were warned about the
5 potential for getting the Hepatitis A virus from the
6 treatment. You were then tested for this virus at the
7 same time and the result was negative?

8 A. Yes.

9 Q. You think this was at a time when they were doing
10 routine screening for the Hepatitis A virus?

11 A. That's correct.

12 Q. Were you warned of any risks of changing your treatment
13 from as-required with Factor IX to prophylactic
14 treatment with Factor IX?

15 A. No.

16 Q. Turning now to paragraph 8 of your statement and finding
17 out that you had acquired HIV virus, you say in about
18 1986 when you were 20 years old you received a telephone
19 call asking you to go in to see Professor Lowe. The
20 records I'm going to refer you to suggest that it was in
21 fact in December 1985, when you saw Professor Lowe.
22 Would that be about right?

23 A. Yes.

24 Q. How old were you? You say you were 20 years old at the
25 time. What were you doing at that time?

1 A. I would have been 19 years old and I was [REDACTED]
2 [REDACTED].

3 Q. You say you had just seen him at your usual clinic
4 appointment the week before, so you weren't very sure
5 why he wanted to see you again. I wonder if I could
6 refer you to WIT0040463. Half way down you will see
7 the entry 12 November 1985:
8 "HTLV-3 positive - send urgent appt [appointment]."
9 And the date there is 2 December 1985. So you say
10 you received a phone call asking you to go to that
11 appointment?

12 A. Yes, that's correct.

13 Q. Was there any explanation as to why you needed to go to
14 that appointment?

15 A. No, I was just asked to attend to see Dr Lowe.

16 Q. Did you have any idea at that point what it might be
17 for?

18 A. No.

19 Q. You mentioned in your statement that you had just seen
20 Professor Lowe the week before. I think if we look in
21 your records at WIT0040464, the appointment before may
22 have been the one that we were looking at before, dated
23 8 November 1985. Along the bottom it says:
24 "HTLV-III -ve. 25/1/85. Given ..."
25 I presume that means Haemophilia Society booklet.

1 Do you remember that appointment at all? It was also
2 the one where your knees are better and you are telling
3 them --

4 A. I'm presuming that was the appointment that then led to
5 the phone call asking me to return for the meeting with
6 Dr Lowe as part of the routine appointments that they
7 would take blood from you.

8 Q. Were you told at that appointment that a previous test
9 had come back negative for HTLV-III?

10 A. I have no recollection of that.

11 Q. Do you have any recollection of receiving the
12 Haemophilia Society booklet that's referred to there?

13 A. Not at that time, no.

14 Q. If we look at WIT0040458, we will see the test result
15 that is mentioned in that clinical note, dated
16 28 January 1985, saying:
17 "HIV negative."
18 Then in brackets:
19 "verbal."
20 I think that's "G Lowe" after it. The date of that
21 specimen is 25 January 1985. So were you aware that
22 that test had been carried out?

23 A. No. I wasn't aware they were testing specifically for
24 HIV. I knew, you know, there were various tests on the
25 blood that was taken as part of the routine screening.

1 I wasn't aware that was one of them.

2 Q. Right. Did you know what HTLV-III virus was at that
3 point?

4 A. Just from -- at that point, you know, there was a lot of
5 publicity around it. So just what you read.

6 Q. Yes. Do you remember how and when you first became
7 aware of the virus?

8 A. No, I am presuming it would just be like most people,
9 just through the press, you know, that there was this
10 virus.

11 Q. Before you found out that you had it, were you worried
12 at all about it?

13 A. I was worried, obviously, because I was taking a blood
14 product and -- so that there was always the risk of
15 transmission.

16 Q. How did you know about that?

17 A. Again, through the press, that this is how it seemed to
18 be -- one way that it could be transmitted.

19 Q. Okay. Could you, please, look at WIT0040459. I think
20 there is the bottom of some other bits of paper shown at
21 the bottom of that but you will see that this is
22 a positive anti HTLV-III result dated 12 November 1985,
23 and the date of the specimen that has been tested is
24 8 November 1985, which goes back to that appointment
25 that we have looked at.

1 A. Yes.

2 Q. So it looks like you gave blood at that appointment?

3 A. Yes.

4 Q. Did you know that that blood was going to be tested for
5 this virus?

6 A. I have no recollection of that, no.

7 Q. Just to complete this picture, I wonder if we could look
8 at WIT0040469, which is a document headed up, if we
9 scroll to the top, "Regional Virus Laboratory,
10 Ruchill Hospital, Glasgow" from Dr Follett to Dr Lowe,
11 saying:

12 "HIV-1 antibody was first detected in a specimen of
13 blood from the above patient and in our laboratory
14 in November 1985. Subsequent testing of specimens from
15 this patient received in prior years and stored in our
16 laboratory indicated that the earliest sample we have
17 positive for HIV antibody is from Nov 1985. A specimen
18 taken in Jan 1985 is HIV antibodynegative. This patient
19 therefore seroconvertedbetween Jan 1985 and Nov
20 1985."

21 That letter is dated 1 November 1988. So that's
22 confirming what we have already seen from the clinical
23 notes.

24 So, going back to the appointment where you were
25 told that you had acquired HIV, you tell us in

1 paragraph 8 of your statement that you went to the
2 appointment alone and at this appointment Professor Lowe
3 explained to you that tests had shown that you had been
4 infected with HIV from blood products and that you were
5 now HIV positive. He told you that they did not know
6 much about the virus. He gave you some leaflets. Can
7 you remember what these leaflets were?

8 A. I think, you know, they were just leaflets about general
9 wellbeing and what was known about HIV at that time.

10 Q. Yes. He discussed with you the dos and don'ts with
11 regard to secondary infection. He told you about the
12 dangers of cuts, blood spills and unprotected sex. He
13 told you to try to lead a healthy lifestyle and to do
14 what you could to keep yourself healthy.

15 A. Yes.

16 Q. He told you that he would continue to monitor you
17 through usual routine checks and then he sent you home,
18 as you put it. You say that although Professor Lowe is
19 a renowned man in his field, you felt that he was not
20 entirely comfortable speaking one-to-one with you about
21 this and it felt to you as if he just wanted to convey
22 the news to you and then move on.

23 A. Yes.

24 Q. You feel that you were told that you were HIV positive
25 in a very matter of fact way and that not a lot of

1 support was offered to you at that time?

2 A. That's right.

3 Q. As you have touched on already, what you knew about HIV,
4 you knew from newspapers --

5 A. Yes.

6 Q. -- and the media?

7 A. Yes.

8 Q. So at that time you thought that the diagnosis or the
9 prognosis of being HIV positive was a life expectancy of
10 eight to ten years?

11 A. That's right.

12 Q. If we go back to the clinical notes of this appointment,
13 which are WIT0040463, these are Professor Lowe's notes
14 of that meeting. They look like it anyway. Was anybody
15 else at that meeting with you?

16 A. No, it was just Professor Lowe and myself.

17 Q. Okay. As you will see, it states:
18 "Counselled re HTLV-3 positivity and NANBH."
19 Which would seem to suggest non-A non-B hepatitis.
20 Do you remember that being mentioned?

21 A. No, I have no recollection of having been informed I was
22 co-infected at that point.

23 Q. Right:
24 "Precautions about blood and sex intercourse. Wears
25 C/sheath."

1 I think the next line reads:

2 Occasional sexual intercourse with one female
3 partner. Will discuss with her and probably bring [her]
4 for testing. Okay to inform GP. Will probably discuss
5 with parents. See Wednesday 4 December, skin tests.
6 Then 11 December with parties.

7 Does that correspond what you think was said at that
8 appointment?

9 A. I certainly recall, you know, obviously being informed
10 that I was HIV positive and that there was then the
11 necessity to also test my partner and that they would
12 have a meeting with my parents, so, yes.

13 Q. Yes. Thank you. I can refer you also to the letter
14 which follows this appointment, WIT0040460. This is
15 a letter dated 16 December 1985, marked "STRICTLY
16 PRIVATE AND CONFIDENTIAL", to your GP. When we go over
17 to the second page, you will see that it's from
18 Professor Lowe.

19 It records that you have been reviewed. You had
20 been reviewed at previous appointments but there was no
21 record of these but he hopes that your GP received some
22 communication from them. It notes you were generally
23 well and currently working, as you have told us, that
24 you had stopped using prophylactic Factor IX concentrate
25 and your knees had been in good condition.

1 You still have Factor IX concentrate as home
2 treatment, although, if your bleeds are relatively
3 infrequent, they may discontinue this in the future.
4 It's noted that on examination you had some small
5 enlarged lymph nodes in the neck and somewhat larger
6 lymph nodes in both armpits but none in the groin. No
7 enlargements of liver or spleen.

8 The next paragraph deals with blood test results and
9 notes in the third line that transaminases were slightly
10 elevated and that they have been slightly elevated in
11 1982, markedly elevated in 1983, slightly elevated in
12 1984 and markedly elevated in January 1985. Hepatitis B
13 surface antigen testing was negative and it's likely
14 that the fluctuating transaminases represent chronic
15 hepatitis due to non-A non-B viruses which are very
16 common in treated haemophiliacs. He goes on to say:

17 "As you may know it has become apparent in recent
18 months that haemophiliacs are also at increased risk of
19 exposure to the HTLV-III virus, which occasionally
20 causes the acquired immune deficiency syndrome (AIDS). The
21 only testing available at the present is an antibody test
22 which was negative in January but which was positive at his
23 last visit suggesting exposure to the HTLV-III virus, presumably
24 in Factor IX concentrate in the past year or so. Accordingly we
25 asked [you] to come back to the clinic on 2 December 1985

1 for counselling concerning this."

2 He then states that you were advised of the positive
3 antibody tests and this indicates exposure to the virus
4 but is not necessarily carriage or infectivity.

5 So he is saying a slightly different thing there,
6 I think, because I think your understanding was that you
7 had acquired the virus after your appointment?

8 A. Yes, it was.

9 Q. Whereas here he is suggesting that you might have been
10 exposed to it but you might not necessarily be infected
11 with it?

12 A. That was -- certainly my understanding was I was HIV
13 positive at that time.

14 Q. He goes on to note:

15 "However, it is wise to assume possible infectivity."

16 And you were advised to be careful with blood and to
17 take care when administering home treatment,
18 particularly with careful disposal of needles, et cetera
19 and would recommend that any blood samples or needling
20 procedures be performed by them from the unit with
21 appropriate precautions and liaison with the hospital
22 laboratories, and suggesting also that dental treatment
23 should be performed by the hospital dentist there, with
24 appropriate precautions.

25 It states you were advised on the possibility of

1 transmission via semen and sexual intercourse and
2 advised to protect sexual intercourse with a
3 contraceptive sheath:

4 "Current information is that most patients with
5 positive HTLV-III antibodies remain well."

6 However, he would like to keep you under regular
7 review, three monthly, he says there, particularly, as
8 you do have some swollen lymph nodes. He records that
9 he saw your mother on 4 December 1985 with you for
10 a further counselling session.

11 Finally, in the last paragraph:

12 "Please let me know if you have any questions
13 concerning this. In view of current media hysteria
14 concerning HTLV-III infection, I am sure you will
15 appreciate the need for confidentiality of this
16 information."

17 How did you feel after that appointment with
18 Dr Lowe?

19 A. I think probably "numb" is the best word to describe how
20 I was feeling at that point. A 19-year old male, to be
21 told that and what you have read in the press, you are
22 thinking, "Well, what does this mean and what does the
23 future look like or lack of it".

24 Q. Do you feel you would have benefited from having
25 somebody with you at that appointment, when you were

1 told?

2 A. In terms of somebody to lean on, maybe, but it wouldn't

3 change the outcome.

4 Q. So what did you do after you were told of your

5 diagnosis?

6 A. I went home and informed my parents.

7 Q. Were you living at home at that point?

8 A. Yes, I was.

9 Q. And how did they react?

10 A. From -- they were obviously shocked, probably as much as

11 I was, and then wanted to -- obviously to speak to

12 hospital to understand what it meant.

13 Q. Yes. Obviously you and your mother went back to the

14 hospital for an appointment --

15 A. Yes.

16 Q. -- on 4 December. We can return to the clinical note of

17 that, which is WIT0040462. It's quite a brief entry,

18 4 December 1985:

19 "Counselled mother re HTLV-III positive."

20 I think that says. Can you remember any more that

21 was said at that appointment?

22 A. I mean, in terms of counselling, my recollection was it

23 was very similar to the discussion I had had previously

24 with Dr Lowe with regard to secondary infection, blood

25 spills, general wellbeing.

1 Q. Right. You say that you thought it was conveyed to you
2 that you were HIV positive. In relation to what that
3 meant for you and what was conveyed to you, were you
4 given any information about that?

5 A. That I was HIV positive?

6 Q. Yes, and what it meant in terms of what might happen,
7 how it might affect you?

8 A. I was advised that inasmuch as what they knew at that
9 point, and obviously research was going into it and the
10 position was changing all the time. So whilst I was
11 given the information that was known at that time, they
12 would continue to keep me informed through further
13 appointments.

14 Q. Right. We can see from the next appointment -- and the
15 date looks either a one or a two at the beginning, 10 or
16 20 December 1985:

17 "Counselled girlfriend that HTLV-III negative, but
18 should have repeat tests - appt to be sent."

19 So I think if we assume it is the latter, your
20 girlfriend had obviously had a test by then?

21 A. Yes.

22 Q. And was being given her negative result. Was that
23 something you asked for or was it something that was
24 offered to you?

25 A. It was certainly offered to me and I discussed it with

1 my girlfriend, who felt that was the right course of
2 action.

3 Q. You say in paragraph 9 of your statement, having
4 referred to that offer by Professor Lowe of the tests,
5 about her being tested and the result being negative,
6 and then you say:

7 "No advice, counselling or support was offered to me
8 or my partner in respect of my diagnosis and, to my
9 recollection, I have never been offered this since."

10 A. No.

11 Q. You tell us in paragraph 10 that you do not know how or
12 when Professor Lowe found out that you had HIV. We have
13 obviously had a look now at the medical records?

14 A. Yes.

15 Q. You say:

16 "I have no idea when I was first tested for HIV and
17 so I don't know how long Professor Lowe knew I had HIV
18 before telling me. I used to give blood samples at my
19 regular clinic appointments."

20 What did you think these blood samples were being
21 used for?

22 A. They were checking your factor level and I also was
23 aware of the concern at the time with regard to
24 Hepatitis A and B.

25 Q. Right. You say:

1 "I was not aware that my blood sample would be
2 tested for HIV and I did not give my consent for this
3 testing."

4 A. No, that's right.

5 Q. You say that you are very angry that you were tested for
6 HIV without being told and without being asked for your
7 consent?

8 A. Yes.

9 Q. That's something you feel that you should have had the
10 chance to do?

11 A. It certainly just gives you the -- I guess, a bit of
12 forewarning: okay, what does this mean should it turn
13 out the worst scenario?

14 Q. Yes, okay.

15 Sir, I'm wondering if that might be a good point to
16 break.

17 THE CHAIRMAN: Yes. We will have a short break at that
18 stage.

19 (2.51 pm)

20 (Short break)

21 (3.12 pm)

22 THE CHAIRMAN: Yes?

23 MS PATRICK: Thank you. David I would just like to take you
24 back to a point you made before the break, about being
25 unaware of the risks involved with your treatment. I

1 want to refer you to paragraph 24 of your statement at
2 0014, and about half way down there you state that had
3 you been told about the risk of these infections before
4 taking the treatment, then you would have weighed the
5 risk up.

6 A. Yes.

7 Q. That you feel that you weren't given the chance to make
8 an informed choice about your treatment, without the
9 knowledge of any risks involved with it?

10 A. Yes.

11 Q. There are a couple of points I would like to make. You
12 will be aware that Professor Lowe has had sight of your
13 statement?

14 A. Yes.

15 Q. I would like to just put a couple of his points on
16 record.

17 A. Okay.

18 Q. The first of these is in relation to the appointment
19 when you were told about your HIV diagnosis - his
20 position is that it was obviously a very difficult thing
21 to do at the time with the uncertainty in relation to
22 the virus?

23 A. Yes.

24 Q. That he was trying to do his best at that meeting with
25 you.

1 Secondly, you told us just before the break that you
2 hadn't been offered any advice, support or counselling.
3 His position is that you were offered, post being told
4 your diagnosis, counselling from Patricia Wilkie,
5 a psychologist in the department, and/or Miriam Guthrie,
6 who was a social worker there.

7 A. I'm certainly aware there was a social worker attached
8 to the department but I have never spoken to her.

9 Q. Okay.

10 THE CHAIRMAN: Patricia Wilkie. Is that a name you know?

11 A. I couldn't have said what her name was. I do know for
12 a while there was a social worker, who was attached to
13 the Haemophilia Unit.

14 MS PATRICK: So moving on, after you found out your
15 diagnosis, you obviously told your parents and your
16 girlfriend. How did your life change after hearing that
17 you had acquired the HIV virus?

18 A. There was huge uncertainty then because you are
19 really -- at that point it was a case of almost living
20 from day-to-day, every indication at that point was you
21 could expect a life expectancy of eight to ten years and
22 each time you attend the unit, you are wondering, "What
23 are my results going to be now? Is it getting any
24 better? Is it worse? Is it stable?" You just don't
25 know.

1 So there was always the anxiety and a general
2 feeling of anxiety, just simply because you had no idea
3 what the future would be like, and I guess being guarded
4 as well in your relationships with people.

5 Q. Did you tell many people, many other people --

6 A. No, none. At that point it was huge stigma within
7 society. So it certainly wasn't something to my mind
8 that you went out and made known to people.

9 Q. So you didn't tell any of your friends?

10 A. No.

11 Q. You didn't tell your brother and sister?

12 A. No.

13 Q. In paragraph 11 of your statement you tell us that, as
14 we saw from the letter we were looking at before the
15 break, at the time you were diagnosed with HIV you had
16 some swelling in some of your lymph nodes and that after
17 being told you had HIV, you carried on attending your
18 regular six-monthly clinic appointments with
19 Professor Lowe. It appears from the medical records
20 that the review appointments may have been arranged for
21 every three months.

22 A. Yes.

23 Q. Could that be right?

24 A. Yes.

25 Q. You say that there didn't seem to be much difference in

1 what happened at these appointments and you saw often
2 a junior doctor and gave blood samples. You say:

3 "I assume that the doctors continued to monitor my
4 HIV status but this was not discussed with me."

5 You weren't referred to any other specialist at that
6 time?

7 A. That's right.

8 Q. Initially you weren't offered any treatment?

9 A. No, it was -- very often I didn't see Dr Lowe. It was
10 just whichever the doctor that was on duty at that time.

11 Q. So was your HIV status discussed at each appointment you
12 went to?

13 A. No.

14 Q. No.

15 A. It wasn't until Dr Seaton took over my care that that
16 was discussed regularly.

17 Q. Right. I would like to refer you to a document
18 WIT0040470. This is showing that you were admitted to
19 hospital for two nights in November 1988, with bleeding
20 gums?

21 A. Yes.

22 Q. Do you remember that?

23 A. Yes, I have a recollection of that.

24 Q. Yes. You had a three-day history of bleeding gums and
25 you had had Factor IX concentrate the night before

1 coming into hospital which had appeared to reduce the
2 bleed. You were referred to the dental department who
3 found that there was no evidence of a source of the
4 bleeding once a clot, which was visible at the back of
5 your upper incisor teeth had been removed, and a swab of
6 your gums was taken for bacteriology. You were admitted
7 to the ward for intravenous antibiotics and made
8 excellent progress.

9 If we refer to WIT0040471, this is a test result
10 of a sample, obviously taken during that admission, and
11 it shows a heavy mixed growth of bacteria.

12 PROFESSOR JAMES: Mouth flora.

13 MS PATRICK: Mouth flora. You will see in the first note:

14 "The significance of this result is doubtful as
15 little is known about the microbiology of dental plaque
16 in HIV-positive individuals."

17 So were you told if this was a consequence of your
18 HIV infection?

19 A. No, I certainly wasn't aware the two incidents were
20 related in any way.

21 Q. Right. Could I refer you next to WIT0040472, which is
22 a letter dated 17 August 1989 from Professor Lowe to
23 your GP. It refers to the latest review and notes that
24 you have been in good general health apart from recent
25 sinusitis and persistent warts on your hands?

1 A. Yes.

2 Q. Did you have warts before you were found to have HIV?

3 A. Yes, I did.

4 Q. You did? Okay. It's noted on physical examination that
5 it was unremarkable apart from bilateral soft axillary
6 lymph nodes of about 1 centimetre in diameter. Further
7 down it's noted that the proportion of CD4+ lymphocytes
8 remained within the normal range.

9 In the second paragraph it's noted there was again
10 persistent elevation of the serum transaminases and this
11 was consistent with chronic non-A non-B hepatitis. It's
12 noted in the third paragraph that you are planning to
13 get married next year.

14 A. Yes.

15 Q. At the very end it's noted you have bloodstaining of the
16 upper gums and you were referred to the dentist who
17 thought there was a possibility of an aerobic infection
18 and you were given intravenous antibiotics to be
19 followed by oral antibiotics.

20 If we could turn to a further review in March 1990,
21 which is WIT0040474, it's noted that you have had no
22 further trouble with your mouth or bleeds since the last
23 review. Your wedding is approaching. It's noted that
24 you have had full discussions with your fiancée of the
25 risk of transmission of HIV infection and you continue

1 to use condoms and precautions with blood. It's noted
2 that:

3 "She does not wish to see our Medical Social Worker
4 or Gynaecologist Dr Hepburn at present, but I again
5 offered their help and advice."

6 In the third paragraph there is a new finding of
7 bilateral enlargement of the axillary lymph nodes, which
8 were about 1 centimetre in diameter and soft.

9 Your weight is increasing and your serum
10 transaminases are still elevated in keeping with chronic
11 hepatitis.

12 You are strongly advised to keep coming to
13 three-monthly clinics, in particular in light of your
14 lymphadenopathy.

15 How did you find attending the clinic appointments
16 in relation to your work?

17 A. It certainly -- it was something I was always vague with
18 work as to why I was attending and I always tried to fit
19 it around a time when I would be on annual leave or
20 there was an easy way to do it without explaining any
21 absences from work.

22 Q. Yes. Was the hospital far from your work?

23 A. Yes, it was probably about 10 miles.

24 Q. Right. If we return to a further letter dated May 1990,
25 WIT0040475, this is once again from Professor Lowe to your GP.

1 In the first paragraph we can see that you are going on
2 holiday to France and you have received advice about
3 insurance for this?

4 A. Yes.

5 Q. What advice was that?

6 A. That was just obviously to make sure that I had medical
7 insurance for going on holiday.

8 Q. Was that something you had difficulty with or you found
9 difficult because of your HIV diagnosis?

10 A. I was certainly aware that, had I openly declared it at
11 the time, then I would not have been given the health
12 cover.

13 Q. Right. So what did you do?

14 A. I didn't declare it then but took the insurance anyway,
15 that covered other risks.

16 Q. Right. It's noted in the second paragraph that you now
17 fall into the category of persistent generalised
18 lymphadenopathy as regards your HIV infection. Your CD4
19 lymphocyte count has fallen slightly to 429 cells per
20 millimetre cubed and you continue to have elevated serum
21 transaminases, consistent with chronic non-A non-B
22 hepatitis. Do you remember if non-A non-B hepatitis was
23 mentioned to you at that time?

24 A. Because it was so long ago, I can't recall. I do
25 remember that the two -- being advised that HIV and

1 Hepatitis C is two distinctive events.

2 Q. Right. Were you aware of non-A non-B hepatitis?

3 A. Not particularly, no.

4 Q. Right. It's noted at the end:

5 "We shall keep him under 3-monthly review and in
6 view of his lymphadenopathy and slight fall in CD4
7 lymphocytes consider the possibility of Zidovudine
8 therapy in the future as there is recent evidence that
9 it may be of value in patients with early progression of
10 HIV infection."

11 Can you remember if that therapy was mentioned to
12 you then?

13 A. It may well have been, I was always resistant to any
14 therapy until -- while I felt well, and there was no
15 necessity to, if you like, to be forced into that
16 decision.

17 Q. So it was something that you were able to discuss with
18 the doctors and they obviously took on board your
19 position or your views in relation to that?

20 A. Yes, that's right.

21 Q. I think we can see in October 1990, WIT0040476, it's
22 noted that there are no symptoms from an HIV point of
23 view. Married life appears to be agreeing with you at
24 this point and it's noted that there are no plans at
25 present for any family, though if this becomes an issue,

1 you will be more than happy to discuss this with them
2 along with your wife?

3 A. That's right.

4 Q. So you were being offered advice in relation to family
5 planning?

6 A. Yes, we married with the intention of always having
7 a family at some point but just not at that time.

8 Q. No. But you were aware that that could be discussed
9 when you wanted?

10 A. Yes.

11 Q. Right. I think in the second paragraph you will see
12 that the HIV Registrar, J. McMenamin, has raised the issue
13 of possible treatment with Pentamidine, that being to
14 prevent infection with pneumocystis pneumonia?

15 A. Right.

16 Q. Do you remember that being discussed with you then?

17 A. It may well have been. In terms of the actual
18 medication, I couldn't recall that. I do recall having
19 discussions around treatment. As I say, I was always
20 resistant to it until it became a necessity.

21 Q. Okay. It also mentions low dose AZT if consecutively
22 your T cell count remains low, and it's noted that you
23 appear to be quite receptive to the idea, although they
24 don't know how far realistically you are from that.

25 Could we turn to a letter of May 1991, the following

1 year. This is from John Petrie, Senior House Officer,
2 to your GP. WIT0040478. This is telling us that you
3 remain asymptomatic. You are not planning a family at
4 present, but you obviously have discussions about
5 starting a family, but not if there is any risk of your
6 wife or child becoming infected:

7 "I had to explain to him that there was in fact
8 a considerable risk of this."

9 A. Yes.

10 Q. This suggests that this may have been the first time you
11 were made aware of that?

12 A. Well, I was always aware of the risk of transmission and
13 while that was a -- while that risk was present, it was
14 something -- I wasn't prepared to put my wife at that
15 risk.

16 Q. You will see in paragraph 3 it's noted about half way
17 down that you are positive for antibodies to the
18 Hepatitis C virus and there has been a substantial
19 decline in your CD4 count since the last assessment, and
20 once again treatment is discussed with you. So this is
21 1991. You say in your statement you weren't informed
22 until 1996 --

23 A. Yes.

24 Q. -- that you had acquired Hepatitis C. So I take it your
25 position is that this wasn't mentioned to you at that

1 time, the fact that you were positive?

2 A. In light of seeing my medical records, I can see now why
3 it would have been earlier than 1996.

4 Q. Right.

5 A. Again, just because of the amount of time that has
6 passed since then, I couldn't recall the exact date.

7 Q. So could you have been told in 1991?

8 A. That would seem -- going by my medical records, that
9 would seem to be the case.

10 Q. Yes. Okay. There is a further letter which might help
11 with this: WIT0040479. This is a review by
12 Professor Lowe. You have been reviewed on
13 10 December 1991. Your general health is reasonable and
14 you are now commuting to Edinburgh, where you have
15 a desk job. In paragraph 2 your weight is steady and no
16 symptoms suggestive of progressive HIV infection.
17 Persistent axillary lymphadenopathy with 2-centimetre
18 diameter nodes in both axillae but no lymphadenopathy
19 elsewhere and examination was otherwise unremarkable.

20 I think there is slight concern at your persistent
21 lymphadenopathy and fallen CD4 cell count at that point,
22 so once again the possibility of treatment is being
23 raised. If you go over the page, you will see that
24 Professor Lowe records that you were positive for the
25 antibody to the recently described Hepatitis C virus and

1 this is probably the cause of your chronic hepatitis.
2 I think you have an infection of your toe at that point.
3 So as you are aware, Professor Lowe's view is that
4 you were told of your Hepatitis C diagnosis in about
5 1991?
6 A. Yes.
7 Q. So you would accept that that's likely to be the case?
8 A. Yes.
9 Q. You tell us in paragraph 13 of your statement that around 1996
10 you and your wife were attending Glasgow Maternity Hospital
11 and saw Mary Hepburn there, who, I think, is a Consultant
12 Gynaecologist?
13 A. Yes.
14 Q. And not a specialist nurse as we have recorded. Were
15 you referred to her by Professor Lowe?
16 A. Yes, we were.
17 Q. Was this for advice in relation to having a family?
18 A. That's correct.
19 Q. What was the outcome of seeing her?
20 A. We went to see Dr Hepburn to -- really to get more
21 information around the options that were available to us
22 at that time. We wanted to have a family as naturally
23 as possible and really risk-free.
24 Q. She looked into the options that might be available to
25 you; is that right?

1 A. That's right.

2 Q. If we could have a look at WIT0040489, this is
3 a letter dated March 1996 from Dr Hepburn to yourself
4 and it is about an option that I think you discussed
5 with her in respect of sperm washing followed by
6 artificial insemination, and she has obviously been
7 looking into this on your behalf?

8 A. That's right.

9 Q. Her colleague in London has told her that due to delay
10 in setting up their service it is not yet available but
11 hopefully will be later in the year. So it's only
12 available in Italy:

13 "He tells me that when he discussed this with the
14 Italian Consultant late last year he was told they had
15 carried out this procedure on a couple of hundred women
16 and so far no woman had become infected as a consequence
17 of this. While the view is that this procedure will
18 lower the risk of passing infection to the woman and
19 will be much safer than conception following unprotected
20 intercourse, there is as yet no proof that this is the
21 case. Many more women would need to be treated to give
22 us this proof so it is still very early days and no matter
23 how many women were treated it would never be possible
24 to give an absolute guarantee of safety."

25

1 A. That's right.

2 Q. "Since there is this element of risk and since the
3 service isn't even available yet I imagine from what
4 you said that you would not want to follow this up."

5 That corresponds with what you told us earlier about
6 you not wanting to consider any risk at all?

7 A. Yes, that's right. Unless they could say to us that
8 that was risk-free, then, as far as we were concerned,
9 it wasn't option.

10 Q. No. So it's noted in the second paragraph:

11 "I have already written to Dr Yates asking him to
12 see you to discuss artificial insemination so
13 hopefully you should hear from him before too long."

14 If we have a look at WIT0040488, this is the
15 letter of referral. If you go over. It's from
16 Dr Hepburn. Could you scroll up again just to get the
17 date? Thank you. February 1996:

18 "I would be grateful if you could see this couple
19 whom I have known for a number of years. I was asked to
20 see them because [you are] HIV +ve and also [has]
21 Hepatitis C and they wanted to discuss the various
22 options available to them should they decide to have
23 children. They have now decided they would definitely
24 like a family but while [he] would obviously like to be
25 the child's father he is not prepared to consider any

1 way of achieving this which could not give an absolute
2 guarantee that [his wife] would not become infected at
3 the time of conception. Since this is not currently
4 possible they have decided that donor insemination
5 would be the best option for them. I understand there
6 is a waiting list of about 14 months for this, and
7 although I understand that [his] condition has been
8 relatively stable since [I] first met him, I wonder
9 whether under these circumstances there is any
10 way this waiting time could be reduced."

11 It's noted your wife is in the process of changing
12 her GP but you have said you don't want this information
13 passed on to either her current or her future GP. Is
14 that right?

15 A. I can't think why we said that. If it's in the records,
16 we have to assume that's correct.

17 Q. Yes. Can we get over to the next page? No, okay, we
18 will leave that letter there. So you tell us in
19 paragraph 19 of your statement that your daughter was
20 conceived by donor insemination and when was she born?

21 A. [REDACTED].

22 Q. Right. You tell us that you and your wife tried for
23 a second child but your wife suffered three ectopic
24 pregnancies and a miscarriage, and you tell us that
25 assisted conception increases the likelihood of ectopic

1 pregnancies?

2 A. That's certainly what we were advised by Dr Yates.

3 Q. Okay. I wonder if I could take you back to your
4 symptoms of HIV and refer to you letter WIT0040487.

5 This is a letter dated 21 November 1995 from

6 Professor Lowe to your GP stating that:

7 You have no symptoms or signs of HIV progression
8 and no clinical evidence of liver disease. Your liver
9 function tests continue to be abnormal with persistently
10 raised level of AST and ALT and raised immunoglobulins.
11 He is waiting further test results.

12 You have been given information on Hepatitis C and
13 the possibility of Interferon treatment. Although it's
14 noted there the results on people who are also HIV positive
15 are not good and at this point your CD4 lymphocyte count
16 remains stable at 278.

17 I think at this point in 1995 there was a slight
18 change in your appointments at the Royal Infirmary to
19 the extent that DrPithie from Ruchill Hospital joined
20 these appointments?

21 A. Yes, that's right.

22 Q. So you effectively would still attend your clinic
23 appointments but you would also see DrPithie from
24 Ruchill Hospital.

25 A. Yes, I didn't attend Ruchill. It was all done through

1 Glasgow Royal.

2 Q. Okay. So you continued to attend these clinics. Your
3 condition continued to be monitored and I think on
4 occasion treatment was discussed?

5 A. Yes.

6 Q. But there didn't prove to be any pressing need --

7 A. No, that's correct.

8 Q. -- for it to be started.

9 Could I refer you to WIT0040494? This is a review
10 appointment by DrPithie of 18 May 1999. It's noting
11 a very slow decline in CD4 count, the most recent count
12 being 337. The percentage is 14 per cent. So he
13 suggests that this indicates you are at risk of
14 opportunistic infection and he suggests that you be
15 started on what I think is Septrin. Is that right?
16 Yes. Do you remember that?

17 A. Yes, I remember taking a tablet at that point.

18 Q. It's noted there that you are remaining reluctant to
19 commence antiretroviral therapy, which you have
20 explained to us.

21 A. Yes.

22 Q. So you started taking that medication then?

23 A. Yes.

24 Q. And carrying on.

25 If we could look at WIT0040496, this is dated

1 16 March 2000 and it's now Andrew Seaton you are seeing.
2 Your viral load is noted to be 87,000 and your CD4 count
3 277. He notes that your viral load has continued to
4 increase to a level at which he thinks treatment would now
5 be indicated, and in addition your CD4 count has dropped
6 a little.

7 This is clearly a very big step for you to take and
8 you are needing time to think these issues over. So he
9 agrees to wait to see what the latest viral load and CD4
10 count are but he is inclined to start Combivir
11 Nevirapine on your next visit, which is in three months'
12 time.

13 What were your concerns about taking treatment?

14 A. Once you started, that was it. I was aware that it
15 would then become part of daily life. I was always of
16 the mindset to ensure that I did what I could to stay
17 healthy and only start taking medication when it became
18 a necessity.

19 Q. So were you --

20 A. I guess there is always that feeling that once you start
21 taking the medication, you know, you are then on
22 a downward spiral.

23 Q. Presumably you had been told about the importance of
24 continuing with the medication once you started it?

25 A. Yes.

1 Q. Yes. What steps were you taking yourself to be healthy?
2 A. Just exercise, watching my diet, I don't smoke, not
3 drinking to any great extent. Just the normal things
4 that your GP would advise you to do.
5 Q. Yes. Despite that, I think your condition remained
6 stable enough that you weren't put on any more -- I
7 don't say you weren't pressurised but you didn't feel
8 a need to start treatment?
9 A. I certainly didn't feel that way. It was a regular
10 discussion that I had with Dr Seaton, that I was always
11 reluctant to go down that road.
12 Q. Obviously you were discussing treatment for the
13 Hepatitis C virus as well. So both conditions were
14 being monitored presumably?
15 A. Yes.
16 Q. Yes. So I think if we move on to May 2002 --
17 A. Sorry, with regard to the Hepatitis C, I wasn't aware
18 there was a treatment at that point.
19 Q. Right.
20 A. It was -- my understanding was they would continue to
21 monitor my liver function test at the reviews but I
22 can't recall having discussed, certainly in 2000 --
23 having discussed a treatment at that point.
24 Q. Could I refer to you a letter, WIT0040497, which
25 is dated July 2000. This is a discussion about treating

1 both really. It notes that you are well with no symptoms
2 attributable to HIV. Your viral load has dropped
3 a little and your CD4 count has gone up. You are happy to
4 defer therapy at present:

5 "We had a discussion today about recognition of
6 symptoms of advancing disease, in particular
7 breathlessness, weight loss and night sweats. If he
8 does start having symptoms then I would like to see him
9 quickly to exclude an opportunistic infection. We have
10 also had further discussion about Hepatitis C. Ideally
11 it would be worthwhile treating Hepatitis C if he has got
12 significant changes on liver biopsy, it would be less
13 problematic if this could be done before he required
14 therapy with antiretro viral agents, currently in
15 discussion about this with the Haemophilia Physicians
16 and we will be putting together a policy in the not too
17 distant future."

18 So that's suggesting that it might be better to
19 treat Hepatitis C first before you start your
20 antiretroviral treatment?

21 A. Yes.

22 Q. But obviously your condition is being monitored and this
23 was just one of many considerations?

24 A. Yes, that's right.

25 Q. I think treatment for your Hepatitis C is mentioned to

1 you again at an appointment in December 2000. This is
2 a letter again from Andrew Seaton. It's noted
3 asymptomatic HIV infection, viral load 54,000, CD4 count
4 585, Hepatitis C infection and Haemophilia B.

5 THE CHAIRMAN: Could I see the number of that?

6 Q.It's WIT0040498.This is December 2000:

7 "Our discussions today focused on management of
8 Hepatitis C. He has a relatively favourable Genotype 3
9 and his HIV infection does not currently need therapy,
10 therefore he would be a good candidate for pegulated
11 Interferon Ribavirin. I have given him some literature
12 to take home and to think about this further."

13 At that stage it seems like treatment is focusing
14 more on the Hepatitis C?

15 A. Yes, I do recall having the discussion with Dr Seaton,
16 that -- once it had been identified, the actual genotype
17 of the hepatitis, and he was able to give me the
18 indication that that type was responding positively to
19 treatment, then it was something I was then more willing
20 to consider.

21 Q. That type being genotype 3?

22 A. Yes.

23 Q. Yes. But I think another two and a half years go by
24 following that and you still manage to resist treatment.

25 Could we refer to WIT0040501? Once again a letter

1 from Andrew Seaton dated 15 May 2002, noting your viral
2 load, 45,000, CD4 count 301. You are very well. You
3 have now decided to go ahead with Hepatitis C treatment
4 after your holiday in July?

5 A. Yes.

6 Q. Yes. Screening bloods have been previously checked and
7 "repeated viral load and CD4 count today".

8 I think if we move on to WIT0040502, we see that
9 circumstances have changed, and unfortunately
10 by July 2002 your CD4 count has dropped substantially
11 from May 2002. It's noted that you are having a lot of
12 minor symptoms which may be as a result of the low CD4
13 count. Can you remember what these symptoms were?

14 A. I do not, I can't -- I can't remember what the symptoms
15 were. I know I had a facial rash at that point. Other
16 than that I can't recall any particular symptoms.

17 Q. Okay. So the discussion at that appointment obviously
18 swung back to HIV treatment options?

19 A. Yes.

20 Q. He notes that he was glad your wife was present today to
21 enter into that discussion. And so the plan is to
22 repeat the CD4 and viral load counts and review you
23 again in a month:

24 "... at which time his probable antiretroviral
25 therapy with either Nevirapine or Efavirenz ..."

1 A. Yes.

2 Q. "... in combination with Combivir will be started.
3 At this stage, we will probably defer Hepatitis C
4 treatment until he is established on antiretroviral
5 therapy."

6 If we look at WIT0040503, your viral load
7 in August 2002 now is 77,000 and your CD4 count is 319.
8 I think there is mention of the rash that you were
9 telling us about.

10 A. Yes.

11 Q. But otherwise you are well. Your CD4 count has gone up
12 but he remains concerned that starting Hepatitis C
13 treatment will inevitably lead to a further drop in CD4
14 count?

15 A. Yes.

16 Q. So it was obviously quite a decision. I mean, it's
17 a hard decision anyway in respect of antiretroviral
18 treatment but treatment for Hepatitis C was obviously
19 another factor that had to come into the equation --

20 A. Yes, that's right.

21 Q. -- while you were deciding what to do. It records that
22 you and your wife have finally come to the conclusion
23 that it's a good time to start treatment. So you are
24 going to do that once you get back from holiday at the
25 end of September. You will be reviewed two weeks after

1 that and by that time you should have had treatment for
2 two weeks of Efavirenz and Combivir, and he gave you
3 some cream for your face.

4 A. That's right.

5 Q. Daktacort.

6 So you started treatments in September 2002. If we
7 look at WIT0040504, a further letter by Andrew Seaton
8 dated 2 October 2002, noting that you started treatment
9 two weeks ago and you are tolerating this very well.
10 You have noticed some vivid dreams with your Efavirenz
11 but these have now subsided. You experience some
12 dizziness but otherwise you are really very well and
13 quite pleased with the treatment.

14 A. That's right.

15 Q. So how often did you have to take the treatment?

16 A. It was daily.

17 Q. Daily.

18 A. The Efavirenz was at night time, the Combivir was two
19 tablets, one in the morning and one in the evening.

20 Q. Right. You had to take them at the same time every day?

21 A. That was recommended the best way, to try and stick to
22 a regime.

23 Q. So did you have any other side effects from the
24 treatment other than those recorded there?

25 A. No, they were the main ones.

1 Q. Okay. If we look at WIT0040505, this is January 2003,
2 it's noted that your viral load is now less than 50
3 copies per ml and your CD4 count is 392, and it's noted
4 that you are tolerating your antiretroviral therapy well
5 with good adherence, and you would like to defer
6 starting Hepatitis C treatment for the next three or six
7 months?

8 A. Yes.

9 Q. I think in fact you didn't start treatment for your
10 Hepatitis C until early 2004?

11 A. Yes, that's right.

12 Q. Is that right?

13 A. I started it in the January of that year.

14 Q. Yes. You tell us in your statement that the side
15 effects of that treatment were draining. You say you
16 didn't suffer as badly as others do but you still went
17 through quite a few side effects yourself?

18 A. Yes, I believe from speaking to Dr Seaton that some
19 patients had a quite horrendous time with it and weren't
20 able to tolerate the treatment because of the side
21 effects.

22 Q. Yes. You tell us that you suffered from exhaustion,
23 depression, nausea, loss of appetite, loss of weight and
24 fatigue?

25 A. Yes.

1 Q. It was like you had flu for a year. Your red blood cell
2 fell and you became anaemic. Did you need treatment for
3 that?

4 A. Yes, I then had to take weekly treatment to combat that,
5 to boost my red blood cell count.

6 Q. What was the treatment?

7 A. It was erythropoietin. It was a weekly injection.

8 Q. You say you used to take the Interferon injection on
9 a Friday and it knocked you off your feet on the
10 Saturday and Sunday and usually the following Monday?

11 A. Yes, that's correct.

12 Q. So did you take it deliberately then so that you could
13 try and keep working?

14 A. Yes, I took it on the basis it was giving me two days to
15 recover from it.

16 Q. You say you managed to keep working for the first eight
17 months of the treatment and then you had to take the
18 last four months off due to the side effects?

19 A. Yes.

20 Q. I think there is a letter in the medical records from
21 your GP recording his admiration for the way you managed
22 to keep going to work whilst experiencing the side
23 effects of this treatment.

24 A. It's certainly not something I ever wish to have to
25 repeat.

1 Q. No. Well, you tell us that within two months of the
2 treatment starting your liver function tests were
3 improving and at the end of the treatment you were told
4 that the Hepatitis C virus was undetectable?

5 A. Yes, it was that that really kept me going through it,
6 knowing that I had responded positively.

7 Q. Did you complete the treatment in January 2005?

8 A. I completed it in December. It was a 48-week course.

9 Q. Right. If we look at letter WIT0040514,
10 dated January 2005. If you scroll down you will see
11 that you are now very well, having now completed a year
12 of Hepatitis C therapy. Your end of treatment response
13 is excellent and your viral load has remained
14 undetectable and you have sustained a good CD4 count.
15 Was that a concern for you during that treatment?

16 A. Yes, I mean, I was certainly conscious that feeling so
17 badly because of the treatment then what sort of impact
18 was that then having on the HIV.

19 Q. It's noted that your haemoglobin has drifted down
20 a little but it's fully expected that this will improve.
21 You tell us that you were told that if the virus
22 remained undetectable for two years, then you would be
23 deemed to be cured of the virus. Is that right?

24 A. Yes, that's right.

25 Q. You spent the next two years just hoping that would be

1 the case and at the end of the two year period in 2007,
2 you were told that you were cured of the virus.

3 A. Yes.

4 Q. You have never had any symptoms of the Hepatitis C
5 virus?

6 A. No.

7 Q. Okay. I wonder if I could refer you to a report which
8 I think you have seen, that Dr Seaton has provided.
9 It's WIT0040700. In the first paragraph you will see
10 that he confirms he has specific responsibility for HIV
11 treatment in the majority of the Glasgow resident
12 haemophiliac patients and that he took over this
13 responsibility from his predecessor, Dr Alan Pithie
14 in January 2000. He has been the Infectious Disease
15 Consultant with responsibility for your care
16 since January 2000?

17 A. Yes, that's correct.

18 Q. Before that and since 1996, DrPithie, as we saw, was
19 seeing you through your clinics at the Haemophilia
20 Department?

21 A. Yes.

22 Q. He records what we have just been through, about your
23 hepatitis. Firstly you commencing antiretroviral
24 therapy and then responding extremely well to it and
25 then going through therapy for Hepatitis C. If we go

1 over the page to page 2, please, he tells us that
2 in October 2008 your antiretroviral therapy was modified
3 and was changed from Combivir to Kivexa. Why did this
4 happen?

5 A. It wasn't through any deterioration in my condition but
6 rather just a concern with regard to the long-term
7 impact of Combivir.

8 Q. He mentions there lipodystrophy. Was that what you were
9 told might be a long-term effect of that treatment?

10 A. Yes, that's right.

11 Q. So how did you find the side effects of Kivexa?

12 A. They are fine. I have tolerated it without any side
13 effects.

14 Q. Good. It's noted in the next paragraph that you have
15 continued to attend regularly at your HIV clinic
16 appointments. You have remained relatively asymptomatic
17 and have tolerated your antiretroviral combination of
18 Efavirenz and Kivexa to date. You have a sustained
19 virological response to your Hepatitis C infection and
20 you are currently Hepatitis C negative.

21 A. Yes.

22 Q. Your last review in the HIV clinic was on 22 March 2011,
23 when you were noted to be very well?

24 A. That's right.

25 Q. I think if I could take you to the bottom of that page,

1 we are going to come on shortly to the impacts of this
2 on you, but he has read your statement and he notes that
3 he entirely agrees that HIV infection and indeed
4 Hepatitis C infection and therapy has hugely affected
5 and impacted on your family life, as we have in your
6 witness statement. Over the page it says:

7 "Finally, on a personal note, I would like to say
8 that having known David since 2000, I have been hugely
9 impressed by his stoical nature, his resolve and his
10 determination to live a fulfilling and normal family
11 life despite the physical and psychological burden of
12 haemophilia and the complicating infections and
13 treatments."

14 So you will have seen that yourself?

15 A. Yes, that's very kind of him to say that.

16 Q. I'm sure it's very well deserved.

17 Turning to the impacts of your infection with HIV on
18 your life, you tell us about these in paragraph 19 and
19 we have touched on the huge impact, as you tell us, on
20 your family life, which is that you and your wife have
21 been unable to have a family naturally.

22 A. Yes.

23 Q. And you feel that but for your HIV infection, you would
24 have had more children, your wife might not have gone
25 through the failed pregnancies and also you tell us that

1 your daughter is not yet aware of how she was conceived.

2 A. That's right.

3 Q. But that this is something you will have to speak to her
4 about in the future.

5 A. Yes, we have to decide at which point she has the
6 maturity to understand that.

7 Q. You tell us in paragraph 20 that you feel that there is
8 huge uncertainty about your future. [REDACTED]

9 [REDACTED]

10 [REDACTED]

11 [REDACTED]

12 A. [REDACTED]

13 [REDACTED]

14 Q. How do you feel your HIV infection has impacted on her?
15 We have already seen the impact in respect of family and
16 the pregnancies.

17 A. Yes. Again, it's just -- you know, it's the long-term
18 outcome. You really are living for the moment and in
19 terms -- not knowing, you know, really how long will
20 I remain well, the impact of having to advise my
21 daughter how she has been conceived. And just there has
22 probably been a -- not so much a lack of honesty but
23 there is always that feeling of holding back with family
24 and friends.

25 Q. Yes. Because you tell us there that you have now told

1 a couple of friends?

2 A. Yes.

3 Q. But nobody else?

4 A. That's right.

5 Q. So that must be very difficult, living with a secret
6 like that?

7 A. Absolutely. It's not a way you would choose to lead
8 your life.

9 Q. Have you received any support about how it might be best
10 to tell your daughter about her conception and when?

11 A. I had asked at the Brownlee Centre if there is a way --
12 any advice that was available with regard to telling --
13 explaining it to children of my daughter's age and also
14 I asked the -- I forget the name now -- the -- sorry,
15 the Macfarlane Trust. However, I have been advised
16 there is no specific information tailored to children.
17 So for the moment it is not something we have addressed.

18 Q. No. You tell us also that you feel you would be wary of
19 moving away from where you live because you feel that
20 you have the support system of the doctors and your
21 family members who know presumably?

22 A. Yes, the support at the Brownlee Centre has been
23 excellent. I can't fault them in any way.

24 Q. You tell us that you have not lost any earnings as
25 a result of having HIV. Financially you and your wife

1 yourself funded two attempts at donor insemination.

2 Your daughter's conception was funded by the NHS?

3 A. Yes.

4 Q. In your attempt to have a second child, you received

5 a grant from the Macfarlane Trust --

6 A. That's right.

7 Q. -- for one more attempt. The NHS funded a further one

8 and you and your wife funded two yourself?

9 A. Yes.

10 Q. You tell us that you receive a monthly payment now from

11 the Macfarlane Trust?

12 A. That's correct.

13 Q. That started in about 2007?

14 A. Yes.

15 Q. You tell us that you and your wife have a mortgage but

16 the life assurance is in your wife's name?

17 A. Yes.

18 Q. You say you think you could get life assurance but it

19 would be at a cost?

20 A. Yes, certainly I'm aware the position with life

21 assurance companies has altered over recent years. So

22 it is something I will have to look at.

23 Q. But in the past have you been put off applying for life

24 assurance?

25 A. I was aware it wouldn't be an option.

1 Q. You say HIV and the Hepatitis C virus have not affected
2 your pension. You say it has only been in the last
3 three years that insurance companies have been willing
4 to provide cover to people with HIV for travel
5 insurance?

6 A. Yes, that's right.

7 Q. But you tell us that it costs double --

8 A. Yes, it does.

9 Q. -- what it should.

10 Is there anything else you wish to tell us today
11 about the effects of being infected with HIV on you and
12 your family?

13 A. I think it is covered in my statement. It is -- it's
14 just the huge uncertainty with regard to the future and
15 it's something that, other than taking the medication,
16 you really have no control over and you feel that there
17 is a lack of empowerment there because it's not
18 something I can control, as I say, other than taking the
19 medication, and there is the anxiety every time you
20 attend the appointments of: am I still stable; I feel --
21 well, I don't feel any different but I'm aware that
22 there could be a lead-in time before any symptoms start
23 to show. For as long as I feel well, there is always
24 the hope that treatments are continuing to evolve and,
25 you know, that -- the carrot out there, that one day

1 they will find a cure for it. There is also the issue
2 of how and when we address it with my daughter and how
3 she will react to that.

4 Q. Yes. That's obviously something that you feel is
5 hanging over you?

6 A. We are -- we do have to address it when we feel the time
7 is right. It has to be done.

8 Q. Okay. I would like to thank you very much for coming
9 today and for telling us this. Thank you.

10 THE CHAIRMAN: David, can I ask you one question, please?
11 You have made it clear that you feel you can't move from
12 the area that you live in. Has that had any indirect
13 implications for your life? Does it affect your
14 employment prospects, for example, or is it simply
15 a matter of keeping close contact with the supporting
16 community?

17 A. It has certainly helped having family close by. For the
18 industry that I'm in, the majority of job opportunities
19 are in England. So we wouldn't want to lose that
20 support network. It is helpful having family and
21 friends round about, and also I have built up a trust
22 with the Brownlee Centre. I'm sure other centres are
23 very capable but I'm comfortable dealing with the
24 Brownlee Centre. I have got to know them and they know
25 me.

1 THE CHAIRMAN: Do you think that it has affected your
2 mobility really?

3 A. It has definitely limited the options when I have been
4 out of work previously, and it does take longer to find
5 suitable employment in Scotland.

6 THE CHAIRMAN: Thank you. That was the sole point I wanted
7 to ask.

8 Gentlemen, content with the evidence?

9 MR DI ROLLO: I was just wondering whether I could just ask
10 one matter in relation to --

11 THE CHAIRMAN: I would like to know what it is. Could you
12 speak to Ms Dunlop and Ms Patrick about it and see if
13 it's a matter of agreement between you how it should be
14 dealt with. That would avoid speaking out loud about
15 it.

16 MR DI ROLLO: Certainly. (Pause)

17 THE CHAIRMAN: I have got fairly strict rules about what is
18 happening. That's why I'm putting Mr Di Rollo through
19 the hoops a little.

20 A. Okay. (Pause)

21 THE CHAIRMAN: I gather everyone is happy, Mr Di Rollo.

22 Questions by MR DI ROLLO

23 MR DI ROLLO: I just want to ask you: you did say in your
24 statement -- you have been asked this already and I just
25 want to ask a bit more information. You do say that it

1 makes you angry -- this is at paragraph 24 of your
2 statement -- that:

3 "I was tested without my knowledge. The doctors
4 must have known, before they tested me, that there was
5 a risk of these infections, as why else would they have
6 tested me? I didn't know about this risk and nobody
7 told me."

8 I just want you to explain, if you can, why it is
9 that you feel angry that you were tested without your
10 knowledge.

11 A. To have tested for it, there has obviously been
12 a concern that the treatment -- there was a risk within
13 the treatment that I was receiving at that time, and
14 prior to that I certainly can't recall any discussions
15 with the hospital with regard to any risks of taking the
16 treatment or any alternatives that were available. So
17 had there been a better course of treatment, I would
18 have wanted to have known that, to have then made that
19 decision for myself.

20 Q. And the actual testing itself without your knowledge,
21 can you just explain why you feel angry about that, if
22 you do feel angry about it?

23 A. Yes, absolutely, I do. You know, as I say, there is --
24 within the medical profession I'm guessing at that point
25 there was a knowledge with regard to the risks within

1 the Factor IX treatment for haemophiliacs. If that was
2 the case, then why had it not been discussed with
3 patients before. And I could understand doing the test
4 as part of routine treatment but make people aware you
5 are going to do that.

6 Q. Thank you.

7 THE CHAIRMAN: I'm just trying to tease it out a little.
8 This is something you felt at the time that the test
9 results were communicated to you, was it?

10 A. Yes, I mean, at the time, yes. At the time it was
11 delivered to me I guess a whole load of emotions go
12 through your head. You know, you're 19 years old and
13 you are thinking at that point, well, am I going to live
14 to see 30. I think -- you know, thinking back on it,
15 it's not at the forefront of your mind and it's only as
16 time goes on that you think, well, how long was that an
17 issue before I became infected.

18 THE CHAIRMAN: That's what I was wondering. It is this sort
19 of thing, that at the time you are told really the
20 impact of the initial communication must have been
21 terrible.

22 A. Yes.

23 THE CHAIRMAN: And that's what would be at the forefront of
24 your mind.

25 A. Absolutely it was.

1 THE CHAIRMAN: But then, as you think over these things and
2 time goes past, one question is: why did I not know
3 about this in advance.

4 A. Absolutely.

5 THE CHAIRMAN: You do you appreciate that, had you known
6 about it in advance, it might not have changed the
7 course of events at all?

8 A. Yes, I understand it. If that was the recommended
9 treatment at the time because the risks of other
10 alternatives were higher, then that's fine, but at least
11 allow me to make that decision for myself.

12 THE CHAIRMAN: That's what I wondered. Really when it comes
13 to the bit, and looking at it after time, you feel that
14 you should have known what the issues were?

15 A. Yes.

16 THE CHAIRMAN: It's your life.

17 A. Absolutely.

18 THE CHAIRMAN: And you should have had a chance to have
19 a say.

20 A. Definitely.

21 THE CHAIRMAN: Is that the way it is to be understood?

22 A. Yes, it is, thank you.

23 MR DI ROLLO: Can I just follow on --

24 THE CHAIRMAN: I'm not sure. I don't want this to stretch
25 forever.

1 MR DI ROLLO: It's the tense of anger. Your statement says:

2 "It makes me angry that I was tested ..."

3 This isn't something that just existed at the time
4 that you were told; it is something that carried on
5 after that?

6 A. Yes, it's looking back on -- thinking back as to the way
7 I was told and the events at the time. As Lord Penrose
8 said, at that point it is not what you are immediately
9 thinking of, you are just trying to deal with what does
10 this mean, and it's only as time goes on that you think
11 back, well, you know, what else was known at that time.

12 MR DI ROLLO: Yes, fine, thank you. Thank you, sir.

13 THE CHAIRMAN: Mr Anderson? And Mr Sheldon?

14 Thank you very much indeed.

15 A. Thank you.

16 THE CHAIRMAN: Now, Ms Patrick?

17 MS PATRICK: That concludes business for today.

18 THE CHAIRMAN: Then we will adjourn.

19 (4.32 pm)

20 (The Inquiry adjourned until 9.30 am the following day)

21

22 FRANCES1

23 Questions by MS PATRICK1

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