

Penrose Inquiry

The following transcript is for Day 75 of the Oral Hearings of The Penrose Inquiry, held on 8th December 2011.

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

Please note that supporting documents referred to by anonymised witnesses during the course of evidence, such as medical records and witness statements, will *not* be hosted on the Inquiry website, in the interests of confidentiality. These supporting documents have been made available on the basis of specific undertakings of confidentiality to the legal representatives of Core Participants and have been considered by Lord Penrose and the Inquiry Team. Except to the extent that they are published by the Inquiry, the evidence given by these witnesses in closed sessions and documents relating to those witnesses are the subject of a Restriction Order made by Lord Penrose under sections 19 & 20 of the Inquiries Act 2005 preventing further disclosure or publication.

Consequently, unlike other transcripts on the Inquiry website, hyperlinking has been disabled throughout.

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Thursday, 8 December 2011

(9.30 am)

STEPHEN

THE CHAIRMAN: Stephen, as you may have gathered, most witnesses are put on oath but since you are anonymous, it doesn't make terribly much sense and we will proceed without that particular formality being carried out.

The other thing is that we have to look after your comfort and you must not hesitate at all if you feel you have a need for a break or anything else at all, just let Margaret know and we will accommodate you?

A. Thank you.

Questions by MS PATRICK

MS PATRICK: Good morning, sir, this morning we are starting topics known as C5 and C6 and Stephen is our first witness this morning.

Stephen, I would like to start by letting you know who everyone is in the room today.

Lord Penrose is on the bench and next to him is Professor James, the medical adviser to the Inquiry. You know Margaret, who is seated next to you, and then coming along the front, we have the two transcribers, who are noting everything that is said today and then we have Maria McCann, who is the secretary to the Inquiry, and next to her we have Oli Stempt, who is in charge of

1 documents today. As I refer you to some of your medical
2 records, these will appear on the screen in front of
3 you.

4 Seated next to me is Laura Dunlop, senior counsel to
5 the Inquiry, whom you have already met and behind her is
6 Lindsay Robertson, who is helping us with this topic.
7 On this side of the hearing room we have the lawyers for
8 the core participants and I think you know the lawyers
9 closest to me, who are representing the patients,
10 relatives and Haemophilia Society.

11 Then we have the lawyers who are representing the
12 Health Board and the Blood Transfusion Service and then
13 closest to you are the lawyers representing the
14 Scottish Government.

15 Some time ago you provided the Inquiry with
16 a witness statement and I hope you have a hard copy of
17 that in front of you. The reference to it is
18 WIT0050927. And your wife also provided a witness
19 statement and I'll refer you to that later, and the
20 reference for that is WIT0050938.

21 You are being known for today's hearing as "Stephen"
22 but that's not your real name. In paragraph 1 you tell
23 us that you are 42 years of age. Is that still the
24 case?

25 A. No.

1 Q. How old are you?

2 A. 44 now.

3 Q. 44?

4 A. Yes.

5 Q. What's your date of birth?

6 A. [REDACTED].

7 Q. Thank you. Are you working at the moment?

8 A. Yes.

9 Q. And what are you working as?

10 A. [REDACTED].

11 Q. [REDACTED]?

12 A. Yes.

13 Q. You tell us in paragraph 2 of your statement that you

14 suffer from Haemophilia A and that this was first

15 diagnosed in 1968?

16 A. Yes.

17 Q. So that would have been when you were about one year

18 old?

19 A. I was 11 months when they found out that I had

20 haemophilia.

21 Q. I wonder if you could have a look at WIT0051217, which

22 is the record of your first attendance at hospital. As

23 you will see, you were admitted on 6 March 1968 and

24 discharged on 9 March 1968. It's noted that you are

25 a cousin of a known haemophiliac, and further down under

1 "Family History", your maternal great grandfather was
2 a haemophiliac too?

3 A. I believe so, yes.

4 Q. And your mother had three brothers but all were
5 unaffected by haemophilia. So were these the only other
6 family members that you knew of who had haemophilia?

7 A. Yes.

8 Q. At that time you were admitted for investigation because
9 of bleeding from your gums and it was noted in the
10 history that you had twice cut your lip on your teeth
11 and had no prolonged bleeding at these times but the
12 present cut has oozed steadily but does not bleed much
13 when you are sleeping. It's also noted that previously
14 you had had a episode of stiffness with pain in one knee
15 at the age of five months and that you have easily
16 bruised since you began crawling.

17 Under "Treatment" we can see that several attempts
18 were made to stop the bleeding by applying adrenaline
19 packs and they didn't work very well and the bleeding
20 was finally stopped after the application of a swab
21 containing Russell's Viper venom, which was held over
22 the bleed for 20 minutes. So that was quite an unusual
23 treatment for haemophilia at that time?

24 A. Certainly I had never heard of it until I read this.

25 Q. But it seemed to work in this case. And then the

1 investigation showed, if we move down the page, that
2 your antihæmophilic factor assay was less than
3 1 per cent of normal activity and that this indicated
4 severe hæmophilia?

5 A. Yes.

6 Q. Your treatment for hæmophilia at the time was as
7 a child at the Royal Hospital [REDACTED]
8 [REDACTED]?

9 A. That's correct.

10 Q. And then at a later stage it transferred to [REDACTED]
11 [REDACTED].

12 A. Yes.

13 Q. According to the medical record, you were next admitted
14 to hospital about four years later, in 1972, when you
15 underwent dental extractions, and at that time you
16 received cryoprecipitate both before and after the
17 dental extractions. The reference for that is
18 WIT0051221, although I don't propose to refer you to
19 it.

20 You therefore continued to receive treatment with
21 cryoprecipitate and including, I think, according to
22 your mother's diary, which you have helpfully let us
23 have a look at, treatment with cryoprecipitate on 13
24 separate occasions in 1974.

25 I have produced hard copies, sir, of Stephen's

1 mother's diary, which is now in court book, but I think
2 the copies may be more legible. I would just like to
3 refer to a few entries of this. The reference for court
4 book is WIT0051698. Do you have copies of these in
5 front of you?

6 A. Yes.

7 Q. I would like to refer you to an entry which is in 1976,
8 2 February; do you recognise this diary?

9 A. Yes, I mean, that's my mother's writing.

10 Q. And she obviously recorded every treatment that you --

11 A. Up until the day I got married, she recorded every
12 treatment. I haven't done it since I got married.

13 Q. Which was quite a big job given the number of treatments
14 you had.

15 A. Yes.

16 Q. Under 2 February 1986 at [REDACTED], two units and then:

17 "New stuff, not cryo, hurt his toe."

18 Then on 23 February at [REDACTED]:

19 "Two units, new stuff. Right toe swollen, x-rayed."

20 From then on there are entries in March and April,
21 where your mother just records units as opposed to what
22 the units are, and then on 24 April, on the next page,
23 in the right-hand column, you can see:

24 "Put into City Hospital, jaundice, serum hepatitis,
25 no treatment, rest, ward 10, discovered eyes yellow."

1 I'm not sure if you will have any recollection of
2 this. Do you?

3 A. I do remember being in hospital, yes.

4 Q. Yes?

5 A. For someone that age to be in hospital for a month is
6 quite a daunting task.

7 Q. Yes, she has noted next to that "32 days"?

8 A. I was in isolation as well.

9 Q. Yes. Then the entry after that, 10 May:
10 "Treatment for toe, six units, back to cryo."
11 Which suggests that your treatment may have reverted
12 at that time to cryoprecipitate?

13 A. Yes.

14 Q. And it might also suggest that the treatment from the
15 February entries that we looked at, through to the time
16 you were admitted with jaundice, were probably the new
17 stuff, which I think we can reasonably assume is
18 Factor VIII.

19 A. Hm-mm. Can I say, when I was on the cryo, we thought it
20 was a matter of what was available because we did go
21 cryo/Factor VIII -- it did sort of go back and forth
22 a number of times before it became solely just
23 Factor VIII.

24 Q. Yes. I think the picture around that time is that it
25 was a mixture of cryoprecipitate, Factor VIII, and it

1 wasn't really until the early 80s that it became
2 consistently Factor VIII, the treatment which you
3 received.

4 As you say, you stayed in hospital about a month
5 then and if we look at WIT0051225, this is the
6 discharge document from the Sick Children's Hospital,
7 and I think you had been referred there. You had been
8 admitted there having spent time in the City Hospital
9 for the last few days of your admission to hospital for
10 this event and, as you will see under "History of
11 presenting complaint":

12 "For four weeks prior to admission he had been in
13 the City Hospital with infective hepatitis."

14 Then you had been discharged home. And you were
15 admitted here for treatment for a bleed.

16 I wonder if you could have a look now at
17 WIT0051231, which shows from about the ninth/tenth
18 entry down, the treatment you received in 1982 in
19 respect of your haemophilia, and if we scroll down this
20 and over the next page, this is
21 showing January, February, March of 1982 and over to
22 WIT0051232, we can see the very lengthy list of
23 treatments that you received in that period.

24 This shows that effectively every third day you were
25 needing treatment due to your haemophilia and at that

1 time were you on home treatment.

2 A. No, I didn't start home treatment until 14/15 maybe.

3 Q. Right.

4 A. So it was a daily trip into [REDACTED].

5 Q. Were you living in [REDACTED] as a child?

6 A. Yes, I missed a lot of schooling in my younger days.

7 Q. I was going to come on to ask you about that because

8 this must have had quite a significant impact on you and

9 your parents trying to obtain the necessary treatment

10 for you?

11 A. Yes.

12 Q. How did this impact on your schooling?

13 A. I can't remember the days but every one of these days

14 I would have been in [REDACTED] for treatment, I would

15 have been off school. Because it was a 32-mile journey

16 there, I would be one or two hours in [REDACTED] and then

17 an hour journey back.

18 Q. Did it impact on your school work?

19 A. It could have, I just didn't let it. Obviously,

20 I caught up and did rather well at school.

21 Q. Did you?

22 A. It was always my mother because my father was

23 a [REDACTED], so he was away from Sunday night until

24 Saturday afternoon. So it was always my mother, she

25 didn't have my father there.

1 Q. Do you have any siblings?

2 A. I have a daughter.

3 Q. Do you have any brothers or sisters, sorry?

4 A. Two sisters.

5 Q. So presumably there was a bit of childcare arrangements
6 going on for your mother as well?

7 A. My sisters are a bit older than me. My sister is 54 and
8 one 50. So probably at this time, they would have been
9 probably old enough to be looked after by grandmothers,
10 aunties, whoever.

11 Q. Did you have family nearby who could help out?

12 A. They are all based in [REDACTED].

13 Q. How about making friends at school; was that affected by
14 being off?

15 A. No, they all knew I was a haemophiliac but it never made
16 any difference to me.

17 Q. Did you ever receive prophylactic treatment?

18 A. Not that I'm aware of, no.

19 Q. You tell us in paragraph 5 of your statement, which is
20 on page 2, that you were treated at [REDACTED]
21 Royal Infirmary by Dr Dawson and Dr Bennett. Can you
22 remember how old you were when you transferred to --

23 A. I think it's about 13/14, when you get transferred from
24 the children's to the main unit.

25 Q. And you say that nothing was ever discussed with you

1 about the risk of infection which might occur from
2 receiving blood or blood products?

3 A. Not that I can recall, no.

4 Q. And that you started receiving synthetic Factor VIII;
5 I think you mention in paragraph 4 that it was
6 in July 1992?

7 A. I think we got that from my mother's diary, I think.

8 Q. In paragraph 6 of your statement, you tell us that in
9 early 1985 Dr Bennett informed you that you were HIV
10 positive?

11 A. Yes.

12 Q. And that he took you into a side room at [REDACTED]
13 Royal Infirmary and told you this and that it wasn't the
14 same as AIDS?

15 A. Hm-mm.

16 Q. You must have been, what, about 18 years old then?

17 A. 17/18, yes.

18 Q. Were you still at school?

19 A. I might have started work, I don't know. It would have
20 been in that area where I might have started. I don't
21 think I was at school.

22 Q. What qualifications did you leave school with?

23 A. Five highers and nine O grades.

24 Q. What did you do after you left school?

25 A. I went to work in a [REDACTED] and then got a degree in

1 [REDACTED].

2 Q. Sorry, I didn't catch that?

3 A. Sorry, I went to work in a [REDACTED] and did night school and
4 got a degree in [REDACTED].

5 Q. So you did night school as well as working?

6 A. Yes, and there was some day release as well, and block
7 release as well.

8 Q. What qualification did you have at the end of night
9 school?

10 A. Well, it's the bank exams. So it's the chartered
11 institute and the membership, and I was awarded
12 a fellowship as well.

13 Q. Right. So you were a hard worker?

14 A. Yes.

15 THE CHAIRMAN: When did you get the fellowship?

16 A. That was May 2006, that would have been. That might
17 have been 2007, it was while I was ill that I actually
18 got the fellowship because I wasn't able to go to the
19 ceremony because I was still on crutches.

20 MS PATRICK: Right. If we have a look at WIT0051245, this
21 is a letter from Dr Bennett to your GP, confirming that
22 your HTLV-III antibody status is positive. As you will
23 see, this is dated 27 February 1986, which is about
24 a year after you think that you were told --

25 A. That would have been the date.

1 Q. Do you think it could have been then?

2 A. It certainly would have been, yes.

3 Q. So you found out in about February 1986?

4 A. Yes.

5 Q. As you will see, Dr Bennett writes:

6 "This is simply to confirm that [your] HTLV-III
7 antibody status is positive. [You] know this. I have not
8 told his parents as this is entirely between [him] and
9 them. I have discussed the situation and some of the
10 implications of this positive test with him when I told
11 him the result. The immediate implication is simply
12 that he has met this virus at some point in the past and
13 has made antibodies to it - the fact that this test is
14 positive does not mean that he has got AIDS. We know
15 that a small but uncertain proportion of people with
16 this positive antibody test do go on to develop AIDS in
17 the future, but we cannot identify those who will."

18 Is this what he said to you at the time?

19 A. I'm not sure if he said all that in words but he took me
20 aside and I knew what he meant, and at that time they
21 had the ads on TV with the falling tombstone, which is
22 quite a hard hitting one if you have ever seen it. He
23 went to lengths to say, "You haven't got AIDS, you are
24 just HIV positive".

25 Q. So what did you know about HIV or HTLV-III at the time

1 you found out that you were positive?

2 A. Not an awful lot, to be honest.

3 Q. Was it something you were worried about?

4 A. Probably at that age, you don't worry about much in life
5 when you are that age. No, I have never let it worry
6 me. I have got it and I have to deal with it. It's
7 just as simple as that.

8 Q. Right. The letter goes on to say the further
9 information that was conveyed to you apparently, about
10 the virus:

11 "I have advised him that although we do not know
12 that this is the case ..."

13 This is referring to the uncertain proportion of
14 people going on to develop AIDS:

15 "... he should regard the fact that this test is
16 positive as meaning that he might pass on the virus,
17 even though we cannot identify it in him. However, the
18 only way that this virus can be transmitted is by sexual
19 activity and I discussed this with him."

20 Do you remember that being discussed with you?

21 A. Yes.

22 Q. "He cannot transmit it to colleagues or family members
23 by normal day-to-day contacts. He gives all his
24 Factor VIII himself and disposes of all his needles and
25 blood products himself. I do not propose to give this

1 information to anyone other than yourself as the only
2 other way of (sic) infection can be transmitted apart
3 from the above, is by injection of [your] blood into an
4 individual, so if a [sample] were to be taken in your
5 surgery, from [you] it should be carefully disposed of
6 and gloves should be used during its withdrawal.
7 I should be glad to discuss this further with you."

8 He goes on to write:

9 "In view of the unnecessary hysteria raised by the
10 press about this subject, in which the infective risks
11 were quite grossly exaggerated, I would not propose that
12 information about HTLV-III antibody positivity should be
13 disseminated more widely than the patient, [your] GP,
14 Dr Dawson and myself, and any laboratory which requires
15 to handle your patient's blood."

16 Did you tell your parents at the time you were
17 diagnosed?

18 A. Yes, I would have told them straight after I come out
19 the room, the first time I met him.

20 Q. How did they react to the news?

21 A. I can't remember. They maybe didn't show it to me but
22 did what any parent would do if I told them that.

23 Q. Did you tell anybody else at the time?

24 A. No.

25 Q. Did you tell your sisters?

1 A. No, not at that time.

2 Q. Do they know now?

3 A. They know now, simply because of what happened later on
4 in my life.

5 Q. When you became ill?

6 A. Yes.

7 Q. So until you became ill, were the only people who knew
8 about this --

9 A. Well, my wife obviously knew because I told her before
10 we got married.

11 Q. But your parents?

12 A. Up until before we got married -- I don't know if I told
13 her in 1990 or 1991, but certainly I told her before,
14 when we were getting plans to get married, that I was HIV
15 positive.

16 Q. You mentioned that and we will come on to that. Did the
17 diagnosis with this affect your life at the time in any
18 way?

19 A. Not really, no. I'm not one of these guys that worries
20 about things. I was football daft and I just carried on
21 playing football as I always had.

22 Q. What else were you spending your spare time on at that
23 time?

24 A. Golf, football, squash.

25 Q. Okay. So very active?

1 A. Yes, which is unusual for a haemophiliac.

2 Q. Yes. And did it cause bleeds?

3 A. Sometimes it did, sometimes it didn't. I was always
4 asked by Dr Bennett, especially to stop playing football
5 but I never did it.

6 Q. Okay. You tell us in paragraph 7 that at the time you
7 were diagnosed, no treatment was offered to you.
8 Basically, since then you have started treatment, which
9 we will come to, but you have never had any symptoms of
10 HIV?

11 A. No, still -- the viral load is still undetectable.

12 Q. And it has been that way since your diagnosis?

13 A. Yes, I mean, I get checked every six months in [REDACTED].

14 Q. So when you left the hospital, having heard that you
15 were positive for HTLV-III, was there going to be any
16 change in your treatment or monitoring by the hospital
17 that you were aware of?

18 A. Not that I'm aware of. Obviously there was an
19 importance placed on discarding of the needles and stuff
20 like that but you just use the bins that you were
21 provided with, that came into hospital to be destroyed
22 when they were full. So I suppose I was maybe told if
23 I cut myself to be aware of who's round about. There is
24 no treatment as such.

25 Q. So you continued to attend the haemophilia clinic for

1 your regular appointments?

2 A. Yes.

3 Q. There is also a record in the medical notes of you asking

4 Dr Bennett to help you in discussing your diagnosis with

5 your girlfriend at the time, in 1987?

6 A. Hm-mm.

7 Q. And we can see that at WIT0051248. As you can see,

8 this is a note, June 1987. I think it refers to you and

9 your girlfriend and:

10 "They are hoping to marry. They wish to discuss

11 the situation with me."

12 I take it from that that the situation is your

13 diagnosis with HTLV-III?

14 A. Can I say that this girlfriend is not my wife now. It's

15 a different individual.

16 Q. Okay. But it says that you are going to organise a day

17 for this and that your girlfriend doesn't know the

18 result of your test, and:

19 "He wishes me to break the news to her."

20 So this was obviously a factor in your relationships

21 at the time, quite a significant one. If we look at

22 WIT0051249 this is a record written by Dr Bruce

23 Bennett, dated 4 June 1987, in the form of a letter and

24 it explains that it's to record the conversation that

25 Dr Bennett had with you and your girlfriend and that you

1 had a prolonged and wide-ranging discussion of the
2 implications of HIV and haemophilia, and you discussed,
3 firstly, the fact that all severe haemophiliac patients
4 in Scotland should be regarded as having met the HIV
5 virus at some stage in the past, regardless of any blood
6 tests. Secondly:

7 "...it is sensible to regard all severe haemophiliac
8 patients as potentially infective and, of course, the
9 commonest means of transmission of the virus is by
10 sexual activity. The most effective means of
11 preventing such transmission is the meticulous and
12 invariable use of sheath." Thirdly, as a result of one
13 and 2, "it's clearly sensible for the partners of
14 haemophiliac men to plan not to conceive in the
15 immediate future."

16 It's noted:

17 "This may seem a very severe stricture, and in fact
18 the incidence of transmission of the virus to the
19 partners of haemophiliac patients or to foetuses they
20 conceive is low, but it is appreciable and cannot be
21 disregarded until the situation becomes clearer."

22 Then fourthly:

23 "When asked about [your] future, I gave what had to
24 be a guarded reply, saying that we could not guarantee
25 that he would not develop AIDS in the future,

1 although he appears in very good health at present. We
2 would of course be keeping a close eye on his
3 wellbeing."

4 Then over the page, number 5:

5 "On the morning of our interview ..."

6 There was an:

7 "... announcement from Glasgow about the vaccine to
8 HIV ... on the radio."

9 Which was obviously a glimmer of hope at the time.

10 Then it concludes:

11 "This seemed more than enough for them to digest at
12 their first interview. I have asked them to go away and
13 think about the situation and to come back and see me at
14 any time they wish in the near future, so that
15 misconceptions about the above, which they will
16 undoubtedly have, can be clarified and new questions
17 which arise in their minds can be answered."

18 I think it implies that your girlfriend will have no
19 difficulty coming to see him and if there are
20 difficulties, Dr Bennett would be happy to see you both
21 at a weekend if you couldn't come.

22 As a footnote, it's noted -- and I think this is
23 your girlfriend:

24 "... did not ask the result of [your] HIV antibody
25 test. I did not volunteer it as I thought she had

1 enough to cope with. As you will see in 1 above, I said
2 that all haemophilic patients should probably be taking
3 similar precautions.

4 "Of course, when she asks, I will tell her the
5 result."

6 So how did your girlfriend find that meeting?

7 A. Dr Bennett was under instruction: in no way tell her
8 that I was HIV positive. This may sound strange but
9 I knew I wasn't going to marry this girl and I was
10 basically forced to, you know, put her in front of the
11 doctor to explain things and that's why I said, "Under
12 no circumstances should you tell this individual". She
13 was a nurse so she probably knew a lot more than any
14 person in the street, and she probably could guess but
15 she wasn't told definitely that I was HIV positive.

16 Q. And you were happy with that?

17 A. Yes.

18 Q. But it's not something everyone has to do when they were
19 in a relationship, is it, seek advice from a doctor?

20 A. No.

21 Q. If we turn to WIT0051262, this is looking at the
22 question of treatment for HIV. This appears to be the
23 first note in the records of treatment for HIV being
24 discussed with you, and this is dated 3 July 1991 and
25 it's from Dr Dawson to your GP. It explains that she

1 saw you to discuss:

2 "... with him the possibility of starting
3 prophylactic AZT. He is quite interested in this. On
4 going over his CD4/CD8 ratios, it was apparent that
5 these have been very variable and at least part of the
6 problem is that the CD8 is rather high. We decided that
7 he would have this repeated on 6 August, as this was
8 convenient to the Immunopathology department, and he
9 went away rejoicing."

10 A. I don't know what that word "rejoicing" means, to be
11 honest.

12 Q. I wondered if there was some relief that you were not
13 starting treatment at that point?

14 A. I don't know. It was just tablets four times a day. So
15 it may be something along the lines of: there is a bit
16 of hope here, there is a treatment, but I certainly
17 wouldn't have used a word as strong as "rejoicing".

18 Q. You tell us that you married in 1992.

19 A. Yes.

20 Q. And after your marriage, you wished to go America. Was
21 this as part of your honeymoon?

22 A. Yes.

23 Q. It was your honeymoon?

24 A. Yes.

25 Q. And as you had the HIV virus, you asked Dr Dawson for

1 assistance travelling there and she took advice from
2 a local travel agent. If we look at WIT0051271 -- did
3 you seek her advice because you were aware it was going
4 to be difficult?

5 A. Yes, because obviously being a haemophiliac and going to
6 America, where we all know the issues with healthcare
7 there, I couldn't just turn up on the doorstep. I had
8 to get proper insurance in place. What I didn't know
9 until I read this note is that she had written to
10 [REDACTED] Tourist Agency to ask for advice.

11 Q. Yes.

12 A. Because [REDACTED] Tourist Agency is one of my clients.

13 Q. Was it?

14 A. So you are probably talking 20 years ago. That person
15 isn't there any more, but I was quite annoyed to find
16 out that she had written -- she doesn't mention my name.

17 Q. She didn't mention your name, no.

18 A. But I was a bit annoyed at the fact that she did that
19 without my know-how, shall we say.

20 Q. Right. Their response is explaining what is required
21 for you to travel to America in 1992 and it encloses
22 a copy of the letter received from the United States
23 consul, together with a visa application form. I'll
24 refer to that in a minute. It also raises the problem
25 in relation to travel insurance and the fact that their

1 own insurance company would only cover you for something
2 like a broken leg, and it wouldn't cover you for
3 anything related to HIV.

4 If we look over at WIT0051272, this is the
5 response from vice consul Janice Fair, dated
6 15 November 1991, and it explains that aliens who are
7 HIV positive are ineligible for a visa under current US
8 law and therefore ineligible to travel under the visa
9 waiver pilot programme. However, the ineligibility can
10 be waived by the immigration and naturalisation service
11 under certain circumstances for non-immigrant, ie
12 temporary visa applicants. Therefore, aliens who are
13 HIV positive must apply for a visa to travel to the US.

14 It notes that:

15 "Since the passage of the new Immigration Act 1990,
16 this ineligibility has been under review.. [they] will
17 continue to process visa applications as before with the
18 required HIV waiver. Generally such visas will be
19 granted only for stays of 30 days or less and only for
20 visits that involve public benefit outweighing public
21 risk."

22 This public benefit is broadly defined and may
23 include family visits, medical treatment and business
24 travel. Were you going to visit family?

25 A. No, we were going on holiday.

1 Q. You were going on holiday?

2 A. Yes.

3 Q. It then states what was needed in the completed
4 application form: a letter from a physician addressing
5 the alien's current state of health, the risk to US
6 public health and the risk of spread of infection, and
7 if you suffer from haemophilia this should include
8 a statement that they will carry and can administer an
9 adequate supply of Factor VIII. It also required
10 a letter for you, outlining the purpose of the trip,
11 your current passport, one photo and a fully completed
12 visa application form.

13 It finishes up by saying:

14 "This office will give full and discreet
15 consideration to any visa application."

16 Dr Dawson did write a letter in support of your
17 application and I know that you made it to America, so
18 that application was successful.

19 A. Yes. I mean, we have been nine times since. The law
20 has slightly changed now and President Obama waived the
21 requirement for a visa waiver in 2009 or something.

22 Q. So that's fairly recent?

23 A. Yes, so when we went back in October, that was the first
24 time I did not have to apply for a visa waiver, but you
25 still get questioned in the customs.

1 Q. I think in paragraph 26 of your statement at page 7, you
2 tell us, the fourth line down, that you had to go once
3 to Belfast for an interview --

4 A. Yes.

5 Q. -- at the American embassy, in order to get a visa
6 because of your HIV?

7 A. Yes, following 9/11 -- you used just to post it down to
8 America but after 9/11 you had to physically appear in
9 person at the embassy.

10 Q. And you say you had to stand in a queue for two to three
11 hours and were only asked about three or four questions,
12 which you had already completed in the application form.
13 And this was a further cost. Was that the travel cost?

14 A. We had a flight to Belfast. I didn't go from [REDACTED].
15 So I had to drive to Edinburgh and had a flight over.
16 Luckily we had friends in Belfast so we didn't have to
17 sit about all day doing nothing. It was just another
18 cost on top of everything else.

19 Q. You tell us about having to fill out a form while on a
20 plane to America, and one of the questions was: are you
21 a Nazi, a terrorist or HIV positive?

22 A. You get these forms. You don't get them now.
23 I think -- is it an ESTA form that you complete now?
24 I can't remember. Everybody got a green form but
25 I always got a white one. There were a number of

1 questions: are you a terrorist, are you a Nazi, are you
2 HIV positive? You can maybe see the resemblance between
3 Nazis or terrorists but not HIV positive. I'm just
4 a simple guy. And obviously that's the one I had to
5 pick, which can be quite degrading to be honest, because
6 you know yourself, if everybody is filling in a green
7 form and somebody sitting beside you is filling in
8 a white form, you automatically think, he is different.

9 Q. Yes.

10 A. Whether they knew why I was filling in the white form,
11 that's a different question, but nonetheless you were
12 being singled out as different.

13 Q. But nonetheless you have managed to go on holiday to
14 America a number of times?

15 A. Yes.

16 Q. Most times needing a supportive letter --

17 A. Not this time because I'm no longer a haemophiliac, but
18 every other time I would have fielded all those
19 documents and proof of insurance and all the rest of it.

20 Q. Yes, we will discuss the difficulties you have with
21 travel insurance later.

22 THE CHAIRMAN: I notice that one of the conditions in the
23 visa arrangements was that you had to have full travel
24 insurance.

25 A. Yes.

1 THE CHAIRMAN: Which can't have been easy in itself.

2 A. We eventually found a specialist firm who specialised in
3 HIV and Hepatitis C related illnesses and haemophilia.
4 So it took a lot of looking about, and it obviously
5 meant telling someone else that you were HIV and Hep C
6 positive. But it was over the phone, so they wouldn't
7 have known me supposing I walked past them today, but it
8 means you were divulging information to another, third
9 party. Very difficult to get but, yes, it can be got.

10 MS PATRICK: And it didn't deter you obviously.

11 A. No.

12 THE CHAIRMAN: How are you doing? You have had about an
13 hour. Are you quite comfortable?

14 A. Yes, I'm fine, no problem.

15 MS PATRICK: If we look at WIT0051279, this is a letter
16 from Dr Dawson to your GP, dated 18 August 1992 and it's
17 referring to you being back from your holiday, looking
18 absolutely in the pink.

19 A. She has got a way with words, hasn't she?

20 Q. She is colourful. But it also notes that you have
21 started on AZT, 250 milligrammes, four times a day. How
22 did you feel about starting the medication?

23 A. I thought it was going to be helpful; it could only be
24 positive. And let's face it, it must have done some
25 good because there are still no signs of it yet.

1 Q. We have heard how important it is to take the medication
2 at the same time each day and not to miss a dose. How
3 did you find --

4 A. I must admit: guilty. I sometimes forgot. I sometimes
5 didn't take. But -- as much as I could remember. But
6 I don't think the AZT -- it didn't have any side effects
7 that I know of. It's quite a powerful drug but I had no
8 issues with it at all.

9 Q. There is a note further on in your medical records that
10 you were warned about over exposure to sunlight when you
11 were on holiday, as a result of this medication?

12 A. Yes.

13 Q. Did it place any other limitations --

14 A. Can I say, I was unaware of that until I was reading
15 these notes. I love the sun. I was in the sun just as
16 much as anybody else was, and obviously it hasn't caused
17 me any issues that we know about, but I was unaware of
18 that fact until I was reading through these. I know the
19 drugs that I'm on now can have some of those side
20 effects but I was unaware of that fact.

21 Q. And so it had no impact at all on your day-to-day life?

22 A. No.

23 Q. After you married, you continued to attend the hospital
24 for monitoring. It's noted in WIT0051281, another
25 difficulty for you was that you were supposed to receive

1 this supply of the AZT from your local chemist but you
2 were worried about doing so because a relative worked
3 there?

4 A. Yes, my cousin's husband is the pharmacist. So we used
5 to pick them up at the pharmacy in the [REDACTED]
6 [REDACTED], which worked well. There were no issues there
7 at all.

8 Q. So still living with the secret at that point?

9 A. Yes.

10 Q. And in 1993 you suffered a pretty severe asthma attack
11 and were critically ill, and there was a scare at that
12 time that it was PCP, as a result of your HIV?

13 A. Hm-mm.

14 Q. But it's noted that it was a delight that no HIV-related
15 disease was found, and I'm not going to look at it but
16 the reference for that is WIT0051285. Were you
17 worried at that time that this was a manifestation?

18 A. No, it turned out that I had glandular fever and didn't
19 know about it, and also we had just took delivery of
20 a cat and the hair -- there is a reaction to the hair
21 more than anything else. I never for a minute thought
22 it was an HIV-related illness.

23 THE CHAIRMAN: It's a cat.

24 A. Yes, it was a Persian cat. You know, these fluffy cats?

25 MS PATRICK: I would like to turn to how you have found out

1 that you had acquired the Hepatitis C virus. You tell
2 us in paragraph 6 of your statement that you were never
3 actually told that you had Hepatitis C. You say further
4 down that it was just something that you became aware
5 of. Is that right?

6 A. To this day I can remember being told I was HIV
7 positive. I can actually see myself walking into the
8 room, sitting down. I could take you to the room,
9 I could tell you where I sat, but the Hep C, nothing.
10 I can't remember anything. I've never been sat down, it
11 was just a case of, "I'm a haemophiliac, I'm HIV
12 positive, I'm bound to be Hep C positive as well," but I
13 cannot remember ever being told, "We have done a blood
14 test, you are Hep C positive".

15 Q. And having looked through the medical records that we
16 have provided to you, has that refreshed your memory at
17 all?

18 A. It says in there that I was diagnosed in 1991. It says
19 somewhere else I was diagnosed in 1999, which is more in
20 line with what I seem to recall. There is mention of
21 1995 and 1996. 1991 I'll disregard because if I was
22 Hep C positive, I would have told my wife before we got
23 married. When my wife became pregnant we asked for
24 a test for HIV, not Hepatitis C because we didn't know
25 I had Hepatitis C. So that takes the 95 and 96 out of

1 it. And, I don't know ...

2 Q. Right.

3 A. But certainly before 1997, we went for an HIV test to
4 make sure my wife -- to see if my wife had been
5 infected. We never asked for a Hep C test but funnily
6 enough we found in my notes, when I was reading them one
7 day, that she actually had been tested for Hepatitis C
8 as well.

9 Q. Yes, there is a test result that she was tested at the
10 same time for HIV and the Hepatitis C virus?

11 THE CHAIRMAN: When was that?

12 MS PATRICK: I'm just looking for that. It was
13 26 September 1996.

14 What I would like to take you through is the medical
15 records briefly on this point. The first mention I have
16 seen in the medical records is on 8 January 1992,
17 WIT0051275. As you will see, this is a letter from
18 Dr Dawson to your GP, dated 8 January 1992, and it
19 states:

20 "The results of the various viral investigations
21 show that [you have] got antibodies to Hepatitis C but has
22 no antibodies to Hepatitis A, so would be susceptible to
23 this if he were going to somewhere where this is
24 endemic."

25 It seems slight by the comment in that letter and it's

1 not specified there that it's discussed with you, and
2 you have no recollection at that time?

3 A. There is no way I would have told my wife I was HIV and
4 not Hepatitis C-positive. Just no way.

5 Q. Then if we look at WIT0051292, this is a "To whom it
6 may concern" letter from Dr Dawson, dated 27 April 1995.
7 It seems to be one of these letters that we have been
8 discussing that you required for your travel.

9 A. Travel to the States, yes.

10 Q. Explaining about your HIV, and your need to carry
11 syringes and needles. In the handwritten notes at the
12 bottom on the right-hand side, it's:

13 "8/6."
14 Which seems likely to have been 8 June. I will take
15 you on to the next letter, which refers to a meeting you
16 had with Dr Dawson on 8 June:

17 "Joints okay. AZT given. Knows about Hep C. Wife
18 had Hep A three years."
19 Then if we scroll down, something about "before
20 holiday".

21 If we look at the next page, WIT0051293, this is
22 the letter which seems to follow those handwritten notes
23 and refers to your haemophilia clinic appointment on
24 8 June. This is a letter from Dr Dawson to your GP,
25 dated 9 June 1995. It explains that you were well at

1 the haemophilia clinic:

2 "His joints were very good indeed. He is
3 Hepatitis C-positive and does not want anything further
4 done about this. He is, of course, HIV positive. His
5 wife had Hepatitis A three years ago but I have offered
6 that we check her out if she wants to. He knows that he
7 can bring her along at any time. Due to come at the end
8 of August ..."

9 Before you go on holiday:

10 "Clinically there were no new physical signs at all.
11 I have given him further AZT and we merely watch
12 developments."

13 A. Again, I will go back. I can't remember Audrey Dawson
14 ever speaking to me about Hepatitis C. It was when
15 Henry Watson came on board. All I can say to that is
16 why didn't we ask for my wife to be tested in 1996, when
17 we found out she was pregnant, for Hep C? I was not
18 aware I had Hep C at that time.

19 Q. Right. You were found to have genotype 3A of the
20 Hepatitis C virus in August 1995. For the record, the
21 reference for that is WIT0051294. If we refer to
22 WIT0051295, this is the next letter from Dr Dawson
23 from your appointment in August 1995. The letter is
24 dated 29 August 1995, explaining that you have
25 genotype 3A, which is one of the genotypes for which

1 interferon is satisfactory. It describes the level of
2 the virus," which I understand meant that:

3 "he would be suitable for interferon therapy."

4 You are noted as having mild transaminitis of 65,
5 with a gamma GT of 120.

6 If we look at the next page, 1296, you are seen
7 again and at this point your liver function tests show
8 a rise and you are about to go off to Florida, and there
9 is no clinical abnormality:

10 "I had checked his hepatitis phenotype etc,
11 but obviously, with his HIV, there would probably be
12 little question of interferon. We will, however, keep
13 him in our Hepatitis C-positive register."

14 Do you remember liver function test results being
15 discussed with you?

16 A. I used to get a blood test every three months but to be
17 fair, I always thought that was to test my CD4 ratio,
18 which was for HIV. They might have said "liver function
19 test" but I wouldn't have associated that with Hep C at
20 that time.

21 Q. The records show that in February 1996, due to a rise in
22 your liver function test results, you underwent an
23 ultrasound. The reference for that is WIT0051300. Do
24 you remember that? It was an ultrasound of your
25 abdomen.

1 A. I'm not going to deny it. If it says I had it -- but
2 whether I was told what that was for -- I mean, in the
3 early days, if someone had said "Hepatitis C" to me,
4 I wouldn't have known it affected the liver.

5 Q. This showed that your liver is enlarged, measuring over
6 17 centimetres in diameter, and several gallstones
7 within the gall bladder and the spleen is also
8 moderately enlarged. I take it you don't remember
9 hearing that?

10 A. No.

11 Q. If we turn to WIT0051301, this is a letter from
12 Dr Watson, who I think is now your haematologist. Does
13 that sound about right?

14 A. Yes, that would have been right, yes.

15 Q. This is a letter to your GP, dated 11 March 1996,
16 explaining that he has reviewed you today in the
17 combined Hepatitis C clinic, referring to the ultrasound
18 evidence of an increased liver size and splenomegaly:

19 "Today I have discussed with him the implications of
20 HCV infection, our plans for its surveillance and the
21 therapeutic options that are available for its
22 treatment. My general impression overall is that he
23 quite sensibly does not wish to have treatment with
24 alpha Interferon just now in view of the side effects,
25 and the very low rate of success for clearance of virus

1 and normalisation of ALT in HIV-infected haemophiliacs.
2 He does agree, however, to undergo endoscopy and I will
3 ask Dr Brunt if he could arrange..." for this in May.

4 The findings of your ultrasound, it's noted, need to
5 be investigated further and a CT scan of your abdomen is
6 then arranged. This subsequently confirms what the
7 ultrasound scan says and the record for the CT scan
8 result is WIT0051302, but I don't propose to look at
9 it.

10 So that suggests a more detailed discussion with you
11 at that time.

12 A. Can I say, he suggests an endoscopy here. The first
13 endoscopy I had was in 2004, I think. It might have
14 been 2003/2004. The reason I say that is I had no idea
15 what an endoscopy was and when I got the endoscopy,
16 I did it without any anaesthetic. I will never do that
17 again for obvious reasons, and I can remember thinking,
18 "Right, what's going on here, what does it entail?"
19 I never had that endoscopy because I think I would
20 remember. So it's either 2003 or 2004 that I had my
21 first endoscopy.

22 Q. Yes. Do you remember a discussion about an endoscopy
23 then?

24 A. To be honest, no. I'm not saying we didn't have
25 a discussion about an endoscopy, whether I understood

1 what that was for. I certainly understood what the one
2 in 2003/2004 was. But it's not a very pleasant
3 experience and I would remember if I had one.

4 Q. So do you remember the implications of your infection
5 with Hepatitis C, the surveillance of it and treatment
6 being discussed with you?

7 A. Again, that's 1996. I am not aware, until some time
8 after my wife fell pregnant, that I was
9 Hepatitis C-positive.

10 Q. You tell us that your wife fell pregnant in 1996, and
11 obviously she was tested for the Hepatitis C virus and
12 HIV in about September 1996.

13 A. We asked for an HIV test. We weren't aware that they
14 were testing for Hep C.

15 Q. If we were to ask Dr Watson about this letter, it's
16 likely that he would say, if he has noted this down and
17 written this to your GP, that it did happen. Is it
18 something that could have happened?

19 A. Anything can happen, yes. I certainly know the
20 endoscopy didn't take place.

21 Q. The discussions --

22 A. HCV -- HIV? It sounds the same if you are not really
23 listening that well, but I can't recall ever refusing
24 treatment at that time.

25 Q. I'm not sure that this is offering treatment. I think

1 it was maybe giving you information about the options
2 that may be there for treatment. Could that have
3 happened?

4 A. Why didn't we ask my wife to be tested for Hep C when
5 she came in in September 1996? That confuses me as
6 well. I didn't know -- when [REDACTED], my wife, went in to
7 get the blood test, it was for HIV, not Hep C. But they
8 did do a Hep C test at the time as well.

9 Q. Yes.

10 A. So I think maybe we will just have to agree to disagree,
11 sort of. I'm not saying this didn't take place but
12 I can't remember it. Certainly I did not have an
13 endoscopy at that time.

14 THE CHAIRMAN: Is there any reference in the medical records
15 to an endoscopy in the week starting 27 May, Ms Patrick?

16 MS PATRICK: No, I don't think so but I will check that.

17 THE CHAIRMAN: Because if there isn't, that would seem to be
18 a fairly clear indication that it didn't take place.

19 PROFESSOR JAMES: There would always be a formal endoscopy
20 report.

21 MS PATRICK: I will have a look at that at the break.

22 THE CHAIRMAN: You know, we have got to try and get through
23 Stephen's evidence and I don't want it to take a huge
24 amount of time, but we can look that up and see whether
25 there is anything that comes out of it.

1 MS PATRICK: So thereafter you continued to attend Dr Watson
2 fairly regularly for monitoring and discussion of
3 treatment. The possibility of triple therapy for your
4 HIV is noted as having been raised with you, if we look
5 at WIT0051312. It's just at the start of the third
6 paragraph. Several aspects of your care, including
7 consideration of triple therapy, but you were content to
8 continue with AZT.

9 A. What I'll say there is I would have taken the
10 recommendations of Henry Watson. If he said, "Stay with
11 what you are on," or, "I recommend this," I would do
12 that. I don't make medical decisions on my own. I'm
13 not qualified.

14 THE CHAIRMAN: How did Henry Watson speak to you? These
15 letters to GPs use a lot of technical language, as you
16 might expect. Did he speak to you in the same language
17 or did he use a sort of more plain English language?
18 Can you remember?

19 A. Not really, no. When you read this, yes, you know, that
20 just goes over my head. I can understand what some of
21 the stuff means but ...

22 THE CHAIRMAN: But my concern with all of these cases is
23 that if a specialist was trying to tell you something
24 about this condition, he wouldn't necessarily use the
25 terms in speaking to you that he would use in writing to

1 your GP. Just as a lawyer doesn't always use
2 complicated language in speaking to a client. He will,
3 if it's going to take a longer time and he gets more
4 money, but that's a different point. But you have no
5 recollection of how it was done?

6 A. No, I mean, I am the type of guy that if I didn't
7 understand, I would ask, to be fair. But if he is going
8 on about triple therapy plasma, no, I don't know what
9 that means. So if he had said to me "Triple therapy
10 plasma", I would just have assumed that was a treatment
11 of some sort and I wouldn't have gone into the depths of
12 what that was.

13 THE CHAIRMAN: If he said to you something like, "There is
14 a new treatment out, it's a bit more complex but how are
15 you getting on with the AZT?"

16 A. I would have said, "Fine".

17 THE CHAIRMAN: I just don't have a feel for it, unless you
18 can tell me. As Ms Patrick has said, there is a clear
19 conflict in recollection, and it's possible that it's
20 just lack of communication.

21 A. I agree with that, yes. Certainly no one put me against
22 the wall and said, "You are Hep C positive". I don't
23 remember the smack in the face that I remember with HIV.

24 THE CHAIRMAN: Yes.

25 MS PATRICK: One point I would make in respect of this

1 letter, it's noted in the second paragraph that you have
2 got swollen parotid glands, which are in front of your
3 ear. Do you remember?

4 A. Yes, he used to call me a "chipmunk" because I used to
5 have bags here.

6 Q. Were you told what was causing those?

7 A. I was under the understanding that was in relation to
8 the HIV.

9 Q. Right. I would like to refer you to a letter of
10 20 March 2000, once again from Dr Watson to your GP.
11 WIT0051316. This is further discussions, I am afraid,
12 about treatment, following a review in the clinic. The
13 second paragraph reads:

14 "Today I have had a fairly frank discussion with him
15 again about the role of antiviral therapy in his case.
16 At the moment I do not think there is any indication at
17 all to change from AZT monotherapy to a combination
18 treatment. Today I have also discussed with him the
19 potential for considering treatment of his Hepatitis C
20 with Alpha interferon/ribavirin. I think there is
21 a reasonable rationale for this given that the major
22 risk factors for HCV progression are male sex and HIV
23 co-infection. Furthermore, at this time it appears that
24 his retroviral infection is progressing very, very
25 slowly with no significant morbidity presently related

1 to it and no significant fall in his CD4 count below the
2 normal level. As such, one has to wonder in this
3 situation what the most likely source of clinically
4 significant disease would be, ie HCV related or HIV
5 related."

6 He refers to one or two small studies, that had been
7 published, of treatment with HCV combination therapy in
8 individuals receiving HIV combination therapy, which of
9 course you weren't; you were still on AZT:

10 "I have mentioned these today. I do not think
11 anything needs to be decided very quickly but I have
12 introduced the ideas to [you] and have had, as usual,
13 a very reasonable discussion with him. At this stage we
14 will continue with monotherapy. When further studies of
15 the use of combination therapy for HCV in the
16 context of HIV therapy are published, then we could
17 reconsider the situation with regards to his liver,
18 which at the end of the day may prove to hold the key to
19 his eventual outcomes."

20 You mention in your statement that you recall in the
21 late 1990s/early 2000 -- this is paragraph 8 -- that
22 Dr Watson said to you:

23 "If I were you, I would be more worried about
24 Hepatitis C than the HIV," and I'm wondering if this
25 was the start of him painting this picture for

1 you.

2 A. Again, I can remember him saying that. At that time

3 I knew I was Hep C positive but I had no idea that that

4 could be, you know, the one that would cause me more

5 harm than HIV.

6 Q. Yes.

7 A. Obviously that ties in with what I said in the statement

8 as well.

9 Q. Yes.

10 A. Like the HIV positive, I remember that because

11 I remember thinking, is there anything more harmful than

12 HIV? Obviously there was. I just didn't know about it

13 at the time.

14 Q. Then there are further discussions, May 2002,

15 WIT0051322. I think, between the appointment we have

16 looked at here, you continued to be monitored. You

17 developed a degree of facial atrophy. Do you remember

18 that?

19 A. You have to explain to me what that is, sorry.

20 Q. I think it's wasting of your face?

21 A. Yes.

22 Q. Which is often a side effect of AZT?

23 A. Okay. I wasn't aware of that but I did have a sort of

24 drawn-in effect.

25 Q. That was after the chipmunk effect?

1 A. Yes.

2 Q. This is a letter from Dr Watson to your GP, dated
3 27 May 2002. The second line:

4 "Today I have had a further discussion with him
5 about the main priorities in his treatment and as time
6 goes on, I am becoming more convinced that his liver
7 disease is more of a threat to him than his HIV per se.
8 As you know, he has a persistent CD4 count of around
9 1000. This has been the case, without much decline, for
10 the last 10 years."

11 The second paragraph:

12 "There are data now that show that HIV infected
13 patients with high CD4 counts can safely be treated with
14 alpha Interferon/Ribavirin, along with anti-HIV therapy,
15 without significant problems. Patients with lower CD4
16 counts tend to do badly. The series of co-infected
17 haemophiliacs is small but success rates of around
18 40 per cent for viral clearance using Pegylated
19 Interferon/Ribavirin have been reported. One option
20 here, which might allow us to inform the debate, would
21 be to consider the possibility of performing liver
22 biopsy, in order to determine what the appearances
23 of the liver are. Today I have discussed all these
24 things with [you] in some detail. I will try to send some
25 references off to him but I have certainly planted the

1 seed in his mind that we should be considering this as
2 a possibility during the course of this calendar year."

3 Do you remember these discussions?

4 A. Yes, because I remember that they were going to put me
5 on the therapy and then, you know, as I went back to the
6 clinic, they didn't seem to speak about it for a while,
7 until -- it would have been 2004, probably. But it was
8 mentioned to me that I would have to start this
9 treatment because they had seen -- I had the type of
10 Hep C that was more likely to clear with interferon than
11 the other type, Hep -- HIV-related illnesses. Don't ask
12 me what they are because I don't know, but I think is
13 there a banding 1, 2, 3, and I was whatever band had the
14 best chance of clearing.

15 Q. 3A, yes.

16 A. But you know, I'll say, yes, I remember this but I do
17 remember, well before actually going on interferon, that
18 we discussed it but it was never brought up again. So
19 I never brought it up to be honest, either.

20 Q. No. How did you feel about having a liver biopsy?

21 A. Again, you will maybe have to check the records.

22 Q. I'll move on to the next document, which is
23 WIT0051324. Which is a letter about a clinic
24 appointment in September 2002 from the specialist
25 registrar, Sajjan Mittal, to your GP. And the second

1 paragraph:

2 "Today I discussed a liver biopsy with him and
3 embarking on pegylated interferon/ribavirin. He wants
4 to have his liver biopsy done early next year
5 in January/February.

6 "On [REDACTED] his liver was palpable, 2fb ..."

7 PROFESSOR JAMES: Finger breadths.

8 MS PATRICK: Thank you:

9 "... below the intercostal margin. Otherwise he has
10 no splenomegaly."

11 There are blood tests noted at the bottom of that.

12 Do you remember why you didn't want to have the liver
13 biopsy until the next year, the beginning of it?

14 A. It sounds as though I spend most of my time in Florida
15 but we were going to Florida in December. Because liver
16 biopsies for a haemophiliac -- it doesn't exactly go
17 hand in hand, so that's why. We would have been flying
18 off at the end of November 2002. And I don't spend all
19 my time in Florida.

20 THE CHAIRMAN: Ms Patrick, it's --

21 MS PATRICK: Yes, that's fine.

22 THE CHAIRMAN: -- about time to rise. I think we should
23 have a little break before you go on.

24 Can I ask you one question. You have spoken about
25 a lot of sporting activities.

1 A. Yes.

2 THE CHAIRMAN: Did you ever go offshore with your father?

3 A. I went in school holidays but not for me. His boat is
4 actually on [REDACTED]
5 [REDACTED].

6 THE CHAIRMAN: I have seen a film of a trawler being lifted
7 over the harbour wall into the Harbour of Refuge. I
8 wouldn't have thought that it was the sort of activity
9 that you would want to indulge in.

10 A. That's probably why I was never encouraged to be
11 [REDACTED]. I did go out. I never really did
12 anything. It was obvious it wasn't for me and I was
13 never really encouraged because I was a haemophiliac.

14 (11.02 am)

15 (Short break)

16 (11.32 am)

17 THE CHAIRMAN: Yes, Ms Patrick?

18 MS PATRICK: Thank you.

19 Stephen, I would like to refer you to a letter dated
20 13/14 November 2002. It's WIT0051325, from Dr Watson
21 to your GP. It refers to an episode when you had a bit
22 of a scare. You had noticed a speck of blood in your
23 boxer shorts and you developed neck pain and stiffness,
24 and it's noted that "For some reason it seemed to
25 convince him that he had developed a diagnosis of

1 cancer." This was investigated and there was found to be
2 no obvious cause for it.

3 But this obviously gave you a fright at the time?

4 A. Yes.

5 Q. And you wondered if one of the reasons for that was the
6 underlying diagnosis you had, which didn't have any
7 obvious symptoms at the time?

8 A. No, I mean, every time I swallowed there was like a lump
9 in my throat, and that's why -- I don't know why.
10 Looking back now, it was rather silly but I thought this
11 lump in my throat was cancer but it transpired it
12 wasn't. I did get some antibiotics because I had some
13 infection.

14 Q. I think at some point you had sinusitis?

15 A. I can't remember what it was. It cleared it up, but I
16 think I got myself into a position I shouldn't have
17 done.

18 Q. It's maybe an indication that although you were
19 continuing to live your life as normally as possible,
20 your diagnosis was still in your mind.

21 A. Yes.

22 Q. Could we turn, please, to WIT0051329. This is
23 a letter from Dr Watson to your GP. It's about a clinic
24 on 17 February 2003. This may be referring to what you
25 touched on there. You were having difficulty still

1 swallowing and had a slight throat infection. This was
2 subsequently investigated and found to be an episode of
3 chronic sinusitis.

4 A. Yes.

5 Q. I wanted to refer you to the fourth paragraph, which is
6 once again about treatment for the Hepatitis C virus:

7 "We had a long discussion about treatment, side
8 effects and expected outcomes. I quoted to him
9 a clearance rate of 40 to 50 per cent using combination
10 therapy with pegylated interferon and ribavirin. He did
11 not want to embark on this over the summer holidays but
12 would be happy to consider it in the autumn."

13 The letter was copied to Andy Fraser. Was he
14 a gastroenterologist?

15 A. Yes, he was a liver specialist.

16 Q. So that he could see make plans for your treatment
17 starting later that year.

18 A. Yes.

19 Q. The medical records show that in May 2003, you were
20 found to have high blood pressure.

21 A. Yes.

22 Q. And the reference for that, although I don't want to
23 refer to it, is WIT0051333, and there was some
24 suggestion from an ECG that you might have left
25 ventricular hypertrophy but the echocardiogram did not

1 confirm that. The reference for that is WIT0051334.

2 After these events, in April 2004, you saw Dr Fraser
3 about starting your treatment. Could you, please, have
4 a look at WIT0051339. This is a letter from Dr Fraser
5 to your GP, dated 26 April 2004, and it notes that he
6 has seen you along with Pauline Dundas, who is the
7 hepatology clinic nurse specialist.

8 In the first paragraph it details a bit of
9 background. It notes at the end of the first paragraph
10 that your liver enzymes have been deranged for some
11 time:

12 "... when last checked at the end of March, he had
13 a bilirubin of 47 and today I thought he looked very
14 mildly jaundiced."

15 Do you remember feeling that you looked jaundiced
16 yourself?

17 A. No, but then none of us thought -- none of my family
18 thought I was jaundiced until I had the liver
19 transplant, and then they saw the whites of my eyes come
20 back. But looking at yourself every day, you don't
21 notice these sorts of things, and neither do your
22 family. The amount of people in my work who had said,
23 "You were so yellow, I wish I had said something," but
24 you just don't see it yourself.

25 Q. No. It notes that your alphetoprotein is elevated at

1 14 and that this can be indicative of hepatocellular
2 carcinoma. It's more likely to reflect cirrhosis in
3 a background of Hepatitis C. So an ultrasound of your
4 liver is going to be arranged.

5 Once again treatment is discussed with you, that
6 there is increasing evidence that Hepatitis C
7 co-infection should be treated in patients with HIV and
8 that Hepatitis C is now the major cause of death in
9 these patients who are co-infected.

10 It's noted that: Three large trials published
11 recently have revealed viral clearance rate in the
12 order of between 25 and 60 per cent, depending on the
13 genotype of the virus encountered. When last tested you
14 had genotype 3A, which is one of the more favourable
15 genotypes for treatment.

16 "I would have to caution this, however, in
17 that if he had cirrhosis as well as HIV infection, his
18 chances of viral eradication would be much lower.
19 I have made him aware of all this. I have also made him
20 aware of the fact that it is likely that he would
21 require 12 months of antiviral therapy with significant
22 side effects and around a 25 per cent chance of being
23 intolerant of the treatment."

24 How did you feel about starting the treatment?

25 A. It was obviously a bit daunting but I knew it had to get

1 done. So that's why I agreed to do it. Unfortunately,
2 it's something I will have to go through again some
3 time.

4 Q. It's noted in the third paragraph that an endoscopy
5 will be performed to see if you have varices and you
6 were in agreement to that but you would not like to
7 consider starting treatment until the beginning of
8 next year "if we feel there would be no significant
9 detriment in him delaying. I have informed
10 him that Hepatitis C virus does appear to be more
11 rapidly progressing in patients with HIV but that it is
12 unlikely that this length of delay will make a major
13 difference.

14 "I suspect that if he has cirrhosis, then he will
15 not tolerate HCV therapy and it may cause him to have
16 hepatic decompensation. I have made him aware of this
17 also. We have given him some literature on Hepatitis C
18 treatment and also some web sources, so that he can get
19 some more information. I will be seeing him when he comes
20 up for his upper GI endoscopy and can answer any further
21 questions he has at that stage."

22 You then had an endoscopy in June 2004, and this
23 disclosed four varices. The plan was that you start
24 propranolol for those?

25 A. Yes, that's what it says. I can't remember the name of

1 all the drugs I was on, I must admit.

2 Q. The notes show that it was planned that you would take
3 that but it was then thought not to be a good idea
4 because of your asthma attack.

5 A. Yes.

6 Q. In July 2004 you had an abdominal ultrasound scan and
7 the result of this is WIT0051342. This is dated
8 6 July 2004. It records:

9 "There is moderate hepatosplenomegaly. Spleen
10 measures 20cm in longest diameter. The liver has
11 a markedly abnormal echo pattern with a nodular
12 heterogeneous appearance consistent with cirrhosis. No
13 focal masses detected. The portal vein is patent with
14 appropriate flow towards the liver." There were stones
15 once again in the gall bladder, normal kidneys. No
16 ascites.

17 So you tell us in paragraph 9 of your statement that
18 you commenced treatment in February or March 2005. If
19 we turn, please, to WIT0051353, this is a letter from,
20 if we look over the page, Lorna Bailey, clinical nurse
21 specialist. Some blood test results are noted at the
22 end of that.

23 If we go back to the first page, 1353, this confirms
24 that on this date, 31 March 2005, you were commenced on
25 antiviral therapy for Hepatitis C. Pegylated

1 Interferon Alpha-2b by subcutaneous injection once per
2 week, and ribavirin capsules daily in divided doses.
3 You were told how to store and administer the drugs and
4 about the follow-up:

5 "It is anticipated that he will receive 48 weeks of
6 treatment. We will, however, check the PCR response at 24
7 weeks and a decision to continue for a further six
8 months will be made at that time."

9 How did you find taking the treatment?

10 A. To start with, it was okay. I must admit I had been
11 told so much about it, and to be given this pack of
12 treatment and told on a Friday night, "You take your
13 first dose," I can remember my wife and I sitting in the
14 dining room with this needle ready to go in, thinking,
15 "What's going to happen when I do this? Is it going to
16 be immediate? Is it going to be through the night?"

17 It was quite daunting but obviously it wasn't until
18 later on that the problems developed. Obviously the
19 problems had been building up without me knowing it
20 because I continued to shrug off what I saw as minor
21 things, but at the end the interferon treatment had
22 every single side effect you can get. Luckily I didn't
23 suffer from depression or felt suicidal but then I had
24 a huge family round about me to keep me going.

25 Q. Do you feel you got a lot of support from your family at

1 that time?

2 A. Well, if it wasn't for their support then... My daughter is
3 the most important person in this world to me. My wife
4 always says, if we didn't have a daughter, I wouldn't
5 have fought so hard. You know, I had mothers, fathers,
6 sisters, aunties, everybody, and unfortunately some
7 people don't have that round about them. Luckily I did
8 and that's, I'm sure, why I pulled through, but I know
9 I'm going to have to start this treatment again. At
10 least I know what to expect but it's not going to make
11 it any easier.

12 Q. No. How old was your daughter at this time?

13 A. What's that, 2005? She would have been --

14 Q. 9?

15 A. 8.

16 Q. 8?

17 A. Yes.

18 Q. And so it's an unknown. You have been told by this time
19 of the side effects that may occur, but you do not know
20 how it's going to affect you personally?

21 A. As I say, I did not know if it was immediately or within
22 24 hours, 48 hours -- how long it would take, but it
23 took a bit longer than that.

24 Q. As you tell us in paragraph 9 of your statement, things
25 went well initially and when your PCR level was tested

1 after the standard six month treatment period, you had
2 cleared the virus. The medical records note that
3 in June 2005 your interferon had to be reduced as there
4 was a fall in your platelets and neutrophils. So when
5 you got the negative test result, when you were in the
6 middle of the treatment, how did you feel about that?

7 A. By the fact that I had cleared the virus, sorry?

8 Q. At that time, yes?

9 A. It was worth carrying on. Obviously, at that stage
10 I had no idea what was in front of me but, you know,
11 I thought this is good. I think the impression we got
12 from the liver consultant was that I would always need
13 a liver transplant, at some time in the future, but it
14 wouldn't be as quickly as it turned out to be. So the
15 hope was that this cleared Hepatitis C and then over
16 a period of time, I would eventually need a liver
17 transplant but things sort of took another route further
18 down the line.

19 Q. It's noted in one clinic appointment visit.

20 THE CHAIRMAN: I think that I have to interrupt a little
21 bit. The Scottish Government Resilience Unit and the
22 Lothian and Borders Police have advised people not to
23 travel in Lothian borders after 2 pm today. And urge that
24 no travel takes place between 2 pm and 9 pm.

25 That clearly has a bit of an impact on us, Stephen.

1 There are implications, of course, for employees and
2 I think that it may affect us. I don't really know how
3 you want to respond to that.

4 MS PATRICK: Well, Stephen, I think you have the furthest to
5 travel out of all of us.

6 THE CHAIRMAN: I know. If it were only Stephen, we could
7 put you up overnight and really avoid exposing you to
8 danger but it's not just you and counsel. We always
9 expect counsel to do whatever is needed to stay on top
10 of things. So I don't bother about them too much but
11 I think --

12 PROFESSOR JAMES: They are expendable.

13 THE CHAIRMAN: I would never dream of saying that, but the
14 staff here are covered by this and I couldn't expose
15 them to danger.

16 MS PATRICK: So when would we need to finish by?

17 THE CHAIRMAN: Do we know yet what is happening with the
18 railways?

19 MS MCCANN: We have had warnings that the services may be
20 taken off. They are not taken off yet.

21 THE CHAIRMAN: We have got to try and go on a little bit
22 further.

23 MS PATRICK: I think it's unlikely Stephen is going to make
24 it home today anyway now.

25 THE CHAIRMAN: With his determination, he is likely to set

1 off whatever happens.

2 MS MCCANN: What if we carried on until 1 o'clock? That

3 would give us a hour to get Stephen back to his hotel

4 safely. Would that be acceptable?

5 MS PATRICK: Yes, keep going until 1 o'clock.

6 THE CHAIRMAN: Yes, keep going until one. The very last

7 thing I want is you heading out back to [REDACTED].

8 A. I can stay as long as it takes. I can work in the

9 hotel. It doesn't matter where I'm at. I can still

10 work, outside work. I don't have to go home tonight.

11 MS PATRICK: If I can take up then, where we left off, which

12 was that initially the treatment was going well and

13 then, as you tell us in paragraph 10, about mid-October

14 you started to feel generally unwell and unable to do

15 things that you normally took for granted. You had

16 continued to work full-time up until then. What was

17 your job at that time?

18 A. It's more of a [REDACTED]. So I was out

19 and about a lot. When I say there was things -- I used

20 to read things and didn't understand what I was actually

21 reading. I had forgotten what I had already read.

22 I was just generally feeling tired and just couldn't

23 do -- I mean, I worked 12/14 hours a day. I just

24 couldn't do that. It was impossible for me to do that.

25 And that's when in October I had to hold up my hands and

1 say -- at this time my employers didn't know there was
2 anything going on in the background with me. I had
3 managed to keep that from them, but at that time I had
4 to hold my hands up and say, "Guys, this is what I'm
5 going through and I need your support."
6 Q. How did they react to that?
7 A. They were absolutely fantastic. I was off for 22 months
8 and they paid me full salary for the full 22 months.
9 You can't ask for more than that.
10 Q. You list in paragraph 14 some of the side effects that
11 you experienced, or which may have been symptoms of your
12 liver disease too, but low levels of concentration, no
13 energy, severe nose bleeds, loss of appetite, thinning
14 of your hair, severe muscle cramps, insomnia, nausea and
15 vomiting. Were you experiencing these symptoms during
16 your treatment?
17 A. I had them all. I remember one time I had cramp in just
18 about every single joint in my body at the same time.
19 There is nothing you can do about it.
20 Q. In October you started treatment for low neutrophil
21 count, so that the interferon could be increased. The
22 reference for that is WIT0051373. You were then
23 prescribed medication for fluid retention. The
24 reference for that is WIT0051374. So having stopped
25 work, presumably you had to stay at home and look after

1 yourself there?

2 A. Hm-mm. My wife had to take time off her work because
3 round about that stage I couldn't do anything for
4 myself.

5 Q. When did your wife stop working?

6 A. I think it was around about January/February time, 2006.
7 I think it would have been.

8 Q. It's noted in her statement, she stopped at the end
9 of October 2006, and didn't work for 14 months.

10 A. It was the year that I got the transplant, I was off,
11 yes.

12 Q. And she says that she didn't get paid during that time
13 she was off work.

14 A. No, I couldn't even go to the fridge and get myself
15 a bottle of juice. Someone had to do it for me. You
16 know, from December 2005 onwards, I was in hospital most
17 of the time anyway.

18 Q. Yes.

19 A. My wife did take some time off work for which she got
20 paid for, but when she took the year and a bit off, she
21 didn't get paid for that.

22 Q. In paragraph 11 you tell us that, on 17 December 2005,
23 you were rushed into [REDACTED]. You had
24 passed a black stool and begun to vomit blood, lots of
25 it. You had a bleed from a varice in your gullet,

1 septicemia and was suffering from liver failure. You
2 went into a coma and didn't regain consciousness until
3 Boxing Day 2005. You were seriously ill and your wife
4 was told that you had only a 40 per cent chance of
5 surviving this illness. Your body was showing signs of
6 shutting down from the inside out.

7 A summary of this rather large event in your life is
8 contained in a letter which subsequently followed that,
9 to the Scottish liver transplant unit, WIT0051402.

10 THE CHAIRMAN: Is this the end of the letter, Ms Patrick?

11 MS PATRICK: Sorry. It's the page before that.

12 If we look at the first page, 1400, this is a letter
13 which followed that but it does give an outline of what
14 happened to you on that occasion. It's a letter from
15 Dr Fraser to Dr Bathgate at the liver transplant unit,
16 dated 27 February 2006, and if we move to the second
17 page of that, which ends 1401, if we move down, starting
18 at:

19 "Unfortunately at week 37 of the therapy ..."

20 This explains what happened to you during that
21 admission. I wonder if it would be easier for everybody
22 just to have a look at that just now and then move on.

23 THE CHAIRMAN: Have you read it yourself?

24 A. Yes.

25 THE CHAIRMAN: Yes.

1 Can we go forward a page, please?

2 MS PATRICK: Your wife was told a couple of days after
3 admission in December that you had a 50/50 chance of
4 surviving that episode. If we look at WIT0051388, we
5 can see notes of a further discussion with your wife
6 on 26 December.

7 If we scroll to the bottom, it's noted -- I'm not
8 quite sure I can make out the name of the doctor noting
9 here but reading from the top:

10 "A long conversation with ..."

11 I'm presuming it was your wife:

12 "I have emphasised that we have short and longer
13 term objectives. The longer term of getting him
14 assessed by the SLTU in Edinburgh depends on getting
15 him through the current episode. The short-term
16 problem, ie to treat the sepsis and establish useful
17 nutrition et cetera, and we are not making progress.
18 He remains pyrexial. The knee seems unchanged. Repeat
19 CT awaited. Change of antibiotics needs to be considered
20 I have emphasised that we will continue with active
21 management at present but that if the condition deteriorates
22 we would have to review the treatment options and resus
23 status."

24 You were obviously very unwell at this time. Has
25 your wife told you since what she was told at that time?

1 A. From what I can remember, what she has told me is it was
2 40/60 chance of surviving, not 50/50, and that, as
3 I said, you know, the body was showing signs of closing
4 down from the inside out. My kidneys, I think, had
5 stopped working. And I think she was basically told to
6 prepare for the worst. I mean, at this time I fell into
7 a coma on 17 December and didn't come round until
8 Boxing Day, the 26th. So my recollection of that is
9 non-existent.

10 Q. No, but it must have been a very anxious time for your
11 family?

12 A. They told me some of the things I was saying and doing.
13 I can't remember. None of them but it wouldn't have
14 been associated with what I normally do.

15 Q. As you say in your statement, you beat the odds and
16 recovered well enough to be discharged from hospital on
17 17 February 2006. The medical records show that you
18 missed a planned holiday that you had in February 2006,
19 and I think you missed other holidays planned for that
20 year as well.

21 A. That wasn't in Florida by the way.

22 Q. No. Can you tell us how you were when you returned home
23 from this admission to hospital?

24 A. By that time I was in a wheelchair, very, very weak, and
25 I think -- does that not coincide -- my wife went off

1 in October, did you say --

2 Q. Yes, your wife's statement said that she stopped working
3 in October 2006. So not quite yet.

4 A. Okay. It must have been the period where she was
5 actually off. I don't know what they called it but the
6 [REDACTED] has got some sort of -- you can take time off to be
7 with a family member.

8 Q. Compassionate leave?

9 A. It maybe was something like that but because I was in
10 a wheelchair, I couldn't do anything myself. The marks
11 on the doors bear fruit of trying to get the wheelchair
12 through the rooms. We had to get a ramp built at the
13 back of the door, just things like that. I wasn't able
14 to do anything myself. All I could do -- I couldn't
15 even go to the toilet myself. It was as bad as that.

16 Because of the knee problem, I couldn't walk, I had
17 no strength to walk. I could do it on crutches now and
18 again. My main mode of transport was wheelchair.

19 Q. Could you tell us briefly about the knee problem that
20 you have touched on?

21 A. The knee problem basically stemmed from my football
22 days. I was left-footed so it was the knee that took
23 all the pressure, all the twists. Any time I had
24 a bleed playing football, it was in the right knee and
25 basically, because I was in a coma and lying, basically,

1 in the same position for a number of days, it basically
2 stuck there in the foetal position, they called it, and
3 it wouldn't move. So there was no way I could have got
4 both feet flat on the floor.

5 Q. And how about feeding? Were you being tube fed at that
6 point or were you managing to feed yourself?

7 A. I was eating but not nearly enough. I was on
8 supplementary drinks and milk shakes. I don't think
9 I was being fed.

10 Q. I think the notes record that you didn't tolerate, at
11 that time, a nasogastric tube, so you were being asked
12 to take supplements instead.

13 A. Yes.

14 Q. How did you feel mentally at that point?

15 A. I just kept on thinking of my daughter, and that's what
16 kept me going. I have said to many people before, that
17 was the set of cards I had been dealt and so I had to
18 deal with it. Make the best of it. There were days
19 when I felt, "What's tomorrow going to bring?" But
20 I never, ever gave up hope, and that's maybe because of
21 the type of person I am, but the family group I had
22 round about me as well. Had I been on my own, who
23 knows? Let's not go there.

24 Q. Okay. And you were then referred, as we saw from that
25 letter, to the liver transplant unit in Edinburgh for

1 a liver transplant. You had to undergo numerous tests,
2 both there and at [REDACTED] subsequently, and the outcome
3 of the assessment is shown at WIT0051422. This is
4 dated 10 May 2006 from Mike Mills, specialist registrar,
5 to PC Hayes, to your GP. It's noted in the first
6 paragraph that: you were admitted electively for
7 consideration for liver transplant on 23 April. You were
8 were not listed on this admission as there were some
9 outstanding issues which need to be clarified
10 first."

11 It then relays a bit of the background, and then in
12 the second paragraph:

13 "During this admission he had also been found to
14 have moderate to severe aortic incompetence, which was
15 not noted before."

16 And they were quite concerned whether this may in
17 fact represent recent infective endocarditis, given your
18 sepsis:

19 "To this end, we have asked for a cardiology opinion
20 and he has to have ... echocardiogram performed as an
21 outpatient, to ensure that there are no vegetations on
22 his valves..."

23 So they are wanting further investigations before
24 considering a transplant. Over the page at 1423, the
25 paragraph starting:

1 "The overall feeling was that he would be a good
2 candidate for liver transplant based on his liver
3 disease, however, in addition to his cardiac
4 dysfunction, there are other areas that would need
5 investigation for A listing, namely that of possible
6 renal impairment."

7 It specified the test that would be needed for that.
8 You were also found to have a random glucose which needed
9 a formal fasting, and 2-hour BPs to determine your
10 diabetic status was required too, and also they want to
11 check your viral loads for HIV and Hepatitis C. This
12 would be significant in trying to formulate a treatment
13 plan.

14 Most of these further investigations were carried
15 out at [REDACTED] and so you had a number of visits to
16 hospital after then?

17 A. Yes, one or two.

18 Q. How did you feel at this time?

19 A. Still tried to remain positive. You can't let it get
20 you down. I had never been diabetic before, so that
21 came as quite a shock. I didn't know I had a heart
22 murmur, which came as a shock. The renal impairment,
23 that just started when I was obviously ill in
24 the December escapade. So we knew about that. But the
25 other two came as a bit of a surprise to us.

1 Q. The glucose tolerance test confirmed a diagnosis of
2 diabetes mellitus type 2. The reference for that is
3 WIT0051438. The echocardiogram suggested mild,
4 perhaps moderate, aortic regurgitation. The outcome of
5 these investigations was that in July 2006, you were
6 admitted to the transplant list. The reference for
7 that is WIT0051454.

8 It's noted on the second page of that letter, which
9 is from Neil Henderson, specialist registrar to
10 Dr MacGilchrist, to your GP, dated 23 July 2006, if you
11 developed a positive HIV viral load, you would be
12 suspended from the transplant list.

13 In paragraph 13 of your statement, which is at
14 page 4, 0930, you tell us that prior to receiving your
15 liver transplant, in the period in 2006 and before the
16 liver transplant in February 2007, you had numerous
17 hospitalisations for a variety of reasons, but mainly
18 due to numerous bouts of hepatic encephalopathy. And
19 you have helpfully drafted a schedule of all your
20 hospital admissions, which can be found at page 10 and
21 11 of your statement.

22 If we look at page 10, we can see that from July
23 to November you were admitted on six occasions with
24 acute confusional state. I would like to refer you to
25 one of the discharge documents about one of these

1 admissions, the one in November, 8 November, 2006,
2 WIT0051486. You tell us that during these episodes
3 you often became drowsy, confused, nauseous, agitated,
4 and with vomiting as well.

5 A. Hm-mm.

6 Q. All very frightening, particularly for your family.

7 A. Yes.

8 Q. This is a letter from Dr Melinda Munang, SHO, to your
9 GP, dated 23 November 2006. It records your reason for
10 admission: increasing drowsiness and agitation.
11 Details your past medical history and a number of
12 medications that by this time you are taking.

13 If we turn to page 1487, you had been due to be
14 admitted for drainage of fluid on the day of admission
15 but presented in the early hours of the morning, after
16 waking up feeling fuzzy in the head, nauseous and
17 vomiting:

18 "These symptoms are well known to him prior to
19 becoming encephalopathic."

20 Then:

21 "He had been well the day before, apart from the
22 [accumulating fluid]."

23 The next paragraph:

24 "Within ten minutes of arriving on the ward, [he]
25 became particularly unwell and dropped his GCS [which]

1 I think is Glasgow Coma Scale] to 3. You had rapid
2 breathing and rapid heart rate but maintained blood
3 pressure and oxygen saturations. "He then had an
4 urgent CT head scan, which showed normal brain
5 appearances and no evidence of haemorrhage."

6 You were treated and within 48 hours your Glasgow
7 Coma Scale grading improved to 15 out of 15, and you
8 were eating and drinking and they were able to take your
9 nasogastric tube out.

10 So quite a frightening episode for you and your
11 family?

12 A. You just got used to them.

13 Q. Yes.

14 A. After the first few, I knew when they were coming on and
15 it all depended how quickly they could get me into
16 hospital. But I think on every occasion, by the time
17 I was there, I was in a coma again so, I never knew
18 anything for 24 or 48 hours. But then between then --
19 again, I'm a very quiet kind of guy but there was times
20 I was doing things that just wasn't me.

21 Q. Did you feel the episodes got gradually worse?

22 A. They did because I asked the question once, is this
23 going to do something to my brain, the amount of
24 episodes I was having. Is it a case of the more you
25 have, you might be left, you know, not 100 per cent,

1 shall I say? But that was confirmed, that that wouldn't
2 be the case, but I think by the end of the time,
3 Andy Fraser had said, you are getting so weak, I don't
4 think you can survive much more of these episodes.

5 Q. Yes. In a letter dated 29 August 2006, which is
6 WIT0051469, you were noted, at your review appointment
7 at the liver transplant unit, to be frail, jaundiced,
8 in a wheelchair and very thin with no nutritional
9 reserve.

10 So you were getting weaker and weaker?

11 A. I came from a guy who had huge upper body strength to
12 being a guy who could do nothing for himself, in
13 a wheelchair. You got photographs, that you will
14 probably see later on, but I just looked like something
15 out of a concentration camp. And that's not how people
16 remembered me. I did a lot of weight training, a lot of
17 exercise, and to be struck down within a matter of
18 months into a wheelchair, it's not the best.

19 Q. Putting it mildly.

20 A. Yes.

21 Q. In October 2006 you attended the liver transplant unit,
22 and the reference for that is 1483. This is a letter
23 from Dr Bathgate to your GP, dated 27 October 2006. At
24 this appointment the matter of live donor liver
25 transplant was discussed with you and your wife, and you

1 were given some information about this. I think that
2 information may be the document which is at
3 WIT0051460, which I don't propose to look at just now
4 but is information that was provided by the Royal
5 Infirmary transplant unit, about bringing in liver
6 transplants. That is about a liver transplant from a
7 non-heartbeating donor, as opposed to a heartbeating
8 donor. That reference is 1460. How did you --

9 THE CHAIRMAN: I'm sure that Professor James can construe
10 the document for me but I would like to know what
11 Stephen has to say about it.

12 Do you remember this document?

13 A. Yes, but you mentioned that was transfer from
14 a non-beating patient?

15 MS PATRICK: Yes, I can show you the document. There are
16 two issues we are discussing with you. I'm sorry,
17 I probably didn't make it clear enough there. You could
18 receive a liver transplant from a non-heartbeating
19 donor, WIT0051460. We can just put it on the screen
20 for you to have a look at. Do you want to have a quick
21 look at it? (Pause)

22 A. I'm maybe getting confused here but I thought I was
23 advised where I could get a matching liver from
24 a sister. Is that not the same thing?

25 MS PATRICK: I think that was also discussed with you too,

1 it's a separate thing.

2 A. I do remember the surgeons when I was in Edinburgh,
3 saying that whatever I needed, I needed a good one. So
4 maybe trying something else may not be the best for me.

5 Q. If you look over at page 2 of this document, there were
6 more risks associated with this.

7 PROFESSOR JAMES: Could I interpret this a little bit? By
8 happy chance I'm a liver specialist myself and was in
9 charge of a liver transplant unit in Newcastle before
10 I retired. So I'm very familiar with this.

11 So effectively, the transplant doctors in Edinburgh
12 must have been very concerned about Stephen's fairly
13 frail state of health already, and one knows that the
14 sort of thinner and weaker an individual is, and
15 superimpose on that the fact that he has got something
16 wrong with a heart valve, it means, in general terms,
17 the less likely he is to recover from the transplant and
18 on the other hand, the "better the liver that he needs".
19 And they knew that Stephen might have to wait quite a
20 long time, actually, as was the case, over six months,
21 before a liver became available, during which time he
22 was manifestly deteriorating, becoming weaker, showing
23 all the very worst complications of very severe liver
24 disease without actually dying.

25 So they must have considered these two other

1 options, the one where effectively you take a liver from
2 somebody who, for example, has died of a heart attack in
3 a hospital and they are able to take a liver out of the
4 dead person, but very quickly after they have died,
5 before the liver becomes damaged. And that's now not
6 very common but it's not infrequently done to increase
7 the supply of donors, because there aren't enough severe
8 road traffic accidents and things like that to supply
9 enough livers in the normal course of events.

10 The other thing that they must have considered,
11 which they were thinking about at that time, was, as
12 Stephen says, the question of what's called a living
13 related donor, usually a family member, in which they
14 have -- remember, you have only got one liver, not two
15 like kidneys -- in which half, or approximately half, of
16 the liver is chopped out of the donor, the wife or the
17 close relative usually, and given to the recipient, in
18 this case Stephen.

19 I'm not aware of what the status of that was in
20 Scotland five years ago but my guess is that that would
21 have been a very exceptional event here, maybe the first
22 or one of the first two or three that was carried out in
23 Scotland. It merely shows the tremendous seriousness
24 with which they viewed Stephen's condition and their
25 keenness to do the very best they could for him.

1 THE CHAIRMAN: Does that sound very much what you feel about
2 it?

3 A. Yes, they always said that I needed a good liver. They
4 did offer me the option of a family relative or close
5 blood match. I'm a great believer that you are in this
6 earth for a defined period of time and you know, it's
7 better for me to wait because I couldn't have had
8 something happening to my sister for me to survive and
9 them not to, I would have rather -- it sounds strange
10 but I would have rather taken the rough myself rather
11 than put somebody else under the strain, because you
12 could never forgive yourself if you did that. But that
13 was discussed. There was two people said they would do
14 it. Unknown to me, one of them actually went to see if
15 they were a match and they weren't. But I would have
16 never have considered it.

17 PROFESSOR JAMES: And Stephen is quite right that for the
18 donor, in these living related cases, this is a big and
19 dangerous operation, with a perceptible mortality,
20 perhaps around 1 per cent, and it's a very big abdominal
21 operation to have half your liver chopped out. So it's
22 an enormous thing really.

23 THE CHAIRMAN: I think that gives us a fairly clear view.

24 MS PATRICK: Yes. Well, the liver transplant was eventually
25 carried out on 1 February 2007, and you tell us that you

1 were the first person with haemophilia in Scotland --

2 A. The first co-infected --

3 Q. Co-infected with cross HIV and Hepatitis C infection to

4 receive a liver transplant. Tell us, if you can, what

5 that process was like for you?

6 A. I was so ill I just wanted it done. I remember the

7 phone call. We had actually been out for a Chinese

8 meal. We came back and I was watching the football on

9 the TV when I got the phone call. Everybody around

10 about me was crying and I was just thinking, "At last".

11 I just wanted to get this done, get it over with and try

12 and rebuild my life again as best as I could.

13 So we went down there. I was in 31 January

14 overnight, and then had various tests done. I still had

15 ascites because I used to get drained every Sunday, and

16 there was a concern that some of that might have an

17 infection but it was all okay and thankfully the deed

18 was done.

19 Q. Yes.

20 A. I do remember -- I was told I needed 17 pints of blood

21 during the operation, because at that time I would still

22 have been a haemophiliac. I think there was just

23 a continual trail between the operating table and blood

24 transfusion to pick-up blood and Factor VIII and what

25 have you, for me.

1 Q. The outcome of that is described in a letter from the
2 registrar to Dr Carol Blair to -- I wonder if I should
3 stop.

4 THE CHAIRMAN: Just go on.

5 MS PATRICK: To the GP, dated 1 February 2007. The
6 reference for that is WIT0051528 and that is the
7 discharge letter after your liver transplant. I won't
8 go into that in detail but it's there in the notes. One
9 point noted was that the transplanted liver, as you have
10 touched on, started producing Factor VIII.

11 A. Yes.

12 Q. So does that mean since then you have no longer required
13 treatment for haemophilia?

14 A. No, apparently my clotting factor is now more than
15 100 per cent. So I don't know how you can get more than
16 100 per cent. I'm no expert.

17 PROFESSOR JAMES: You got two for the price of one at least
18 with that liver, didn't you?

19 A. It's the only good thing that has come out of this.

20 Q. You were discharged from Edinburgh Royal Infirmary on
21 23 February 2007 and returned to [REDACTED]
22 [REDACTED], where you remained until 6 April 2007.
23 Could we, please, look at WIT0051111. I think this is
24 a photo of you celebrating your 40th birthday in
25 [REDACTED].

1 A. You wouldn't recognise that as me today, would you?

2 Q. No.

3 A. I hope not.

4 THE CHAIRMAN: Well, we can celebrate that by my telling you
5 about the trains. Take a wee bit of the tension out of
6 the air maybe.

7 Most, if not all trains have now been cancelled. So
8 travel between Edinburgh and Glasgow is not possible at
9 the moment. What will happen is that the building will
10 be kept open here for as long as necessary, to let the
11 travel situation settle down.

12 You will be transported to your hotel, where you can
13 work to your heart's content, and that's that. But
14 I think there is very little else that one can do at the
15 moment. There is little point in stopping since the
16 transport arrangements have already been completely
17 disrupted, and we will just have to try and react as
18 best we can. I suspect that being inside here is the
19 best place we can be for the time being.

20 MS PATRICK: Okay.

21 THE CHAIRMAN: So ...

22 MS PATRICK: We will proceed.

23 THE CHAIRMAN: Proceed.

24 MS PATRICK: In paragraph 16 of your statement, at page 4
25 you tell us that following the transplant, you never

1 really made the recovery that you had been hoping for.
2 You developed complications which saw you hospitalised
3 again after only one week of being discharged from the
4 hospital. And on 13 April 2007, you were re-admitted to
5 hospital and this was due to swollen legs and breathing
6 difficulties.

7 A summary of your condition then is contained in
8 WIT0051554. After your admission to hospital, your
9 heart condition steadily deteriorated and an
10 echocardiogram revealed steady deterioration and signs
11 of decompensated heart failure. This is noted at
12 WIT0051540, but I don't propose to refer to that.

13 It was felt that you needed urgent aortic valve
14 replacement but the surgeons in [REDACTED] were very
15 concerned about the risks to you of this procedure and
16 were not keen to proceed with that. Your poor prognosis
17 at that time was discussed with you and your wife on
18 18 April. The notes recording this are WIT0051546.
19 These were extensive notes, with updates from various
20 doctors involved in your care at this time, many through
21 a day. But this one is at 5 o'clock on 18 April 2007,
22 discussion with -- I think we can take it that that's
23 your wife and you:

24 "I have explained the seriousness of [his] current
25 condition and our current management plans. They had

1 not appreciated how seriously ill [he] has become and were
2 understandably tearful at the news that the prognosis is
3 poor. I have explained that we will discuss dialysis
4 and that we will show the echo pictures again to
5 cardiothoracics. It would be useful to ensure that all
6 those involved in his care agreed with the prognosis and
7 management strategy."

8 The nursing notes record that that night you slept
9 very little as you were understandably very scared. The
10 [REDACTED] team informed the liver transplant unit at
11 Edinburgh Royal Infirmary of your deterioration and the
12 Edinburgh Royal Infirmary agreed to take you down for
13 assessment. And on 19 April 2007, you were transferred
14 down by blue light ambulance to Edinburgh Royal
15 Infirmary.

16 How were you and your wife at this point?

17 A. Well, I think the biggest shock came -- when I was
18 re-admitted on the 13th, it was with swollen legs,
19 obviously ascites, and struggling breathing. We thought
20 it was asthma. We had absolutely no idea it was
21 anything to do with the heart. So when someone comes
22 and tells you you have got two to three days to live, it
23 came as a huge shock and we understood why the surgeon
24 wouldn't do the surgery required, but I'm not going to
25 say that I agreed with it but what option did we have?

1 I was told to go home and basically die at home.

2 Q. It's recorded in your notes, as you left for Edinburgh
3 those at [REDACTED] would be there for you
4 if the worst happened, and you returned home and the
5 reference to that is WIT0051553.

6 As you say in paragraph 16 of your statement,
7 initially the surgeons in Edinburgh considered that the
8 surgery was too risky but they sought another opinion
9 from the Freeman unit in Newcastle. The reference for
10 this is WIT0051558. By this time you had developed
11 renal failure as well. It's at the bottom of this page:

12 "Freeman unit Newcastle contact for second opinion.
13 They would proceed with valve replacement. Formal
14 referral asked, however, 'lack of beds ITU' makes
15 transfer not possible. Given the disparity, a decision
16 has been made to obtain another opinion on Sunday.
17 [Mr Campanella]. Keep full medical support until Monday."

18 So Mr Campanella was asked if he would agree to
19 operate on you and he did agree to do that. I think we
20 have a couple of other photos, which I think were taken
21 just before --

22 A. That was the day before, because my wife thought that
23 would be the last photograph of me still alive.

24 Q. 1109. And 1110. This was the day before your
25 surgery. Yes.

1 So, as you say, the operation was carried out and
2 you survived it against all the odds.

3 A. Yes.

4 Q. Were you given odds before you went into the operation?

5 A. Can I just say one thing? If it hadn't been for my wife
6 demanding a third opinion, and in consultation with my
7 liver surgeon, Mr Hidalgo, I think I would have just
8 been left. But my wife managed to persuade -- she said
9 I would rather tell my daughter that her dad had died on
10 the operating table than just to be left to waste away
11 until he died at home. And I have two people to thank.
12 It's my wife and Mr Campanella. If it wasn't for them,
13 I don't think I would be here today. The odds were "We
14 need a miracle". It was less than 1 per cent. You
15 can't get worse odds than that.

16 Q. No. You transferred back to [REDACTED] in
17 about July 2007 and from then, presumably, you had to
18 start rebuilding yourself. We have seen that you were
19 very thin and were you still in a wheelchair at that
20 point?

21 A. Yes, I was in a wheelchair for almost two years. Bear
22 in mind when I had the heart op, I would have been less
23 than six stone in weight. Standing at 6 feet 3 and less
24 than 6 stone doesn't really go hand in hand.

25 Q. And you tell us that you then returned to work part-time

1 at the end of July 2007?

2 A. Yes.

3 Q. And that you worked out that over these 22 months that
4 we have been talking about, you had spent 309 days in
5 hospital between [REDACTED] and Edinburgh. You tell us
6 that this was an extremely traumatic time for your
7 family but in particular your wife and daughter.

8 Your daughter was only eight years old when your
9 illness started and your wife had had to take the time
10 off work to be by your side, and presumably that took
11 her away from your daughter?

12 A. 107 days in Edinburgh, my wife was there every day. So
13 my daughter was being looked after by friends, family,
14 sisters, whoever. She came down every second weekend
15 but ...

16 I wasn't nice to look at. So they tried to protect
17 her as best they could.

18 Q. And she obviously knew how serious things were for you
19 because you tell us that:

20 "Telling her that I was going to die and watching
21 her face is something that I will never, ever forget."

22 A. I wanted to tell her because I didn't want that to be
23 left to my wife, had I died. So we told her that and
24 let's hope I never have to do it again. I don't know
25 what she was thinking. I'll never ask her. But she

1 must have been thinking something.

2 Q. Yes.

3 Sir, in paragraph 7 to 13 of the wife's statement,
4 she describes some of the impacts of this on her.

5 I think that would be best, for time's sake, to be taken
6 as read.

7 THE CHAIRMAN: Taken as read, yes.

8 MS PATRICK: So since then you tell us that you have made
9 a full recovery from the liver disease and your heart
10 operation. You have continued to attend for review and
11 monitoring at the transplant unit in Edinburgh, and your
12 latest review there was March 2010, WIT0051686.

13 I'm sorry, I'm going to take you to 1690 instead,
14 which is later. This is dated 29 September 2010 and it
15 records that you are doing remarkably well, playing golf
16 and winning trophies.

17 A. I'm not as good a golfer as I was but I wouldn't expect
18 that because I used to be good.

19 Q. And your blood test results are over the page on 1691.

20 You tell us in paragraph 20 that you still attend
21 [REDACTED] and have blood tests every
22 three months and your heart is tested once a year.

23 A. Yes, that has now changed to the liver once every six
24 months, and the heart is once every two years now.

25 Q. You have reduced your medications from 49 tablets a day

1 to 13.

2 A. Yes.

3 Q. That must be a welcome relief. You say:

4 The diabetes is likely to have been caused by
5 your liver disease and the pressure it put on your
6 pancreas.

7 At paragraph 19, you say, as you have touched on
8 already, that you still have HIV and Hepatitis C and
9 that you know you will have to have treatment once again
10 for Hepatitis C. What have you been told about this?

11 A. I do know that in a liver transplantee Hepatitis C comes
12 back more aggressive. So I have got something nice to
13 look forward to.

14 You know, I will have to do it again. I have been
15 told because I'm so well and -- I mean, when I started
16 that treatment I was obviously ill for a lot longer than
17 we realised. So hopefully it won't be so traumatic with
18 the various side effects that I will have, but I will
19 have to go through it again. But at least I'll know the
20 things to look out for this time.

21 Q. And do you feel you have any symptoms of either of these
22 viruses at the moment?

23 A. I have never had anything from the HIV. Hepatitis C?
24 Not that I am aware of but then I'm no medical expert.
25 Certainly if there had been something, the doctors would

1 have told me by now because I would have been started on
2 the treatment again.

3 Q. Yes. In paragraph 21 you start to tell us about the
4 effects of these viruses on your life and you tell us
5 about your golfing, the fact you used to play badminton
6 and squash and work out and do a lot of training to keep
7 fit, and obviously you lost the ability to do that for
8 a long period of time. Have you gone back to all of
9 these?

10 A. No, I will never manage to play badminton and squash
11 because of the knee. I have started playing golf again.
12 I do some training but not as much. I can't go and run
13 three or four miles, as I used to do. It's basically
14 just weight training. Once you get to my age, it takes
15 a lot harder work to build up what I had before, as to
16 when you are younger.

17 Q. Yes. Do you feel that having these viruses has affected
18 friendships that you have had, or your social life?

19 A. Well, on the basis nobody knows I'm HIV -- I don't think
20 it would. I don't think HIV would because, when I say
21 I don't have a lot of friends, I mean really close
22 friends. I have friends but the Hepatitis C -- I have
23 a great bunch of friends and it has made no difference
24 to them whatsoever.

25 Q. In relation to your work, you have already told us how

1 good your employers were and how you received your full
2 salary and so there was no loss of income from your
3 periods off work. Did you miss your work at the time
4 you were unable to do it?

5 A. I take a great comfort -- bearing in mind that I could
6 easily sit and get incapacity benefit, et cetera, if
7 I want to, but that's just not my make-up. I had my
8 heart operation on 26 April and I was back at work on
9 27 July. I think that speaks wonders of myself, without
10 trying to blow my own trumpet. Three months from an
11 operation that I had less 1 per cent chance of survival,
12 being back at work. If only more people in the country
13 were like me, it wouldn't be in such a state as it is
14 today.

15 Q. You tell us in paragraph 29 that before your illness --
16 was this before you started treatment with interferon
17 and ribavirin? -- you were up for promotion at work.

18 A. Yes.

19 Q. And you were told that you would have got the promotion
20 within a few months had you not been off ill. You say
21 that you lost out on £12,000-plus salary increase and
22 the associated substantial salary-related bonuses.

23 A. Yes.

24 Q. Did you lose any bonuses as a result of being absent
25 from work?

1 A. I got a bonus the first year I was off but not the
2 second year.

3 Q. And would you have done had you not been off work?

4 A. Yes, because your bonus is based on your salary, so even
5 10 per cent of 12,000 is a lot, and -- so, yes, although
6 I was paid full salary, it would have been a lot more
7 had I been promoted. And now I have got the promotion
8 but didn't get the salary increase because the world
9 turned upside down when I was off.

10 Q. You tell us also in paragraph 24 that you have a staff
11 mortgage through your work.

12 A. Yes.

13 Q. But you have no other life cover other than for this
14 mortgage. There are no staff mortgages allowed now so
15 you wouldn't be able to move house, as you feel that you
16 wouldn't be able to get another mortgage as a result of
17 being unable to get life assurance of any description?

18 A. Well, we probably could get a mortgage but if I die,
19 I don't want to leave my wife a debt. So I'm not
20 prepared to take that risk. I wouldn't get a staff
21 mortgage. But, you know, rules have changed. You don't
22 necessarily have to provide life cover but I don't want
23 to go and take out a mortgage for whatever it is and
24 then die and leave my wife with a debt. She would have
25 to sell the house. She would have enough to cope with

1 on my death than worry about things like that.

2 Q. Have you looked into getting other life assurance?

3 A. There is no point. I mean, I have because -- as soon as
4 you mention a couple of things, without going into any
5 depth, there is no point. It's bad enough getting
6 travel insurance, let alone life assurance.

7 Q. There was a note in your medical records -- I don't know
8 if you noticed it -- that in 1986 you had made an
9 application for life assurance and they wrote to your
10 doctor asking for you to undergo a HTLV-III test and
11 your application for life assurance was then withdrawn.

12 A. It was withdrawn by me because I knew they were going to
13 say no. I started working in 1984 and applied for this
14 life cover, as you do when you start working, and then
15 obviously, when I realised that -- the fact that I was
16 HIV-positive and what that meant for life cover, rather
17 than have them decline it, I pulled it.

18 I mean, at the moment I have -- I don't have a big
19 mortgage; that's not a great hassle. But would my life
20 cover pay out? I think they would probably try not to
21 if they could because it was one of these things
22 where -- because you are in [REDACTED], you
23 automatically get cover for your mortgage. So I didn't
24 lie by saying I did not have HIV; they never asked the
25 question because it's just a given right that you get

1 life cover.

2 Would they pay out? I would think they would
3 contest it but the amount is so small -- it really is --
4 it doesn't matter. But we certainly couldn't move house
5 to a bigger house, which we probably do need. We will
6 just have to extend it when we can.

7 Q. And in paragraph 25 you tell us that you have a work
8 pension, which you have touched on there, which has
9 a death in service benefit of four times your salary.
10 You say:

11 "I can't really change jobs as I wouldn't get any
12 death in service benefit as a result of my condition."

13 A. I mean, that's the only life cover I have, so I really
14 am stuck to where I am. Okay, we get money from the
15 Macfarlane Trust and the Skipton Fund but once I die,
16 that stops. I have been offered a number of jobs with
17 other financial institutions, offering huge salary
18 increases, but there is no point. I mean, I did take
19 one further -- when I was actually given the job and
20 given a pay increase to stay, little did my manager know
21 I had no intentions of going anywhere because I know
22 I couldn't, but it severely limits my ability to further
23 my career outside [REDACTED].

24 Just two weeks ago I had someone on the phone asking
25 me if I was prepared to consider moving. I'm not into

1 wasting anybody's time -- and that would have been for
2 an 8-grand salary increase. I don't know whether
3 I would have done it, but it's an offer, it's there, I
4 cannot even consider because there is no point.

5 Q. You feel these options are closed to you now?

6 A. Yes. Who is going to give me four times life cover of
7 salary? No one. Okay, we could all die tomorrow but
8 ... Obviously, with what I have, it would be a huge
9 concern to an underwriting company and they just
10 wouldn't do it. So, if I move, I would lose the
11 four times that I have and receiving nothing, and I'm
12 very aware of leaving my wife and daughter with nothing
13 because all they will get from me is what we have got in
14 the bank and they can't live on that forever.

15 And not a lot of things annoy me or upset me about
16 what went wrong but that stops me providing for my wife
17 and daughter in the way that I wanted. It's just life.

18 Q. In paragraph 26 you tell us about having to pay £687 for
19 travel insurance to America, which would have been only
20 £200 had you not had any medical conditions. Would
21 haemophilia have impacted on that figure of £200 and
22 made that more?

23 A. Probably not because I wasn't a haemophiliac at that
24 time. By the way, for October this year it was £854
25 I had to pay. So it's going up.

1 Q. And that sometimes needs a medical report from your
2 doctor?

3 A. No, because I have been with the same company for -- as
4 long as I confirm there is no deterioration in any of
5 the conditions, they are happy just to -- that's maybe
6 why it increases every time. But I have had letters
7 from Andy Fraser, the liver consultant, and the heart
8 consultant, saying I'm probably less likely than anyone
9 else in this street, because I get checked so often, of
10 there being anything wrong with me. But they don't pay
11 any attention to that.

12 So if you take it that it's £854 for a three-week
13 holiday in America, you can only guess what my life
14 assurance premium would be, if someone was willing to
15 quote.

16 Q. Yes. You touched on it a bit earlier, but you have
17 received both payments from the Skipton Fund and
18 a payment from the Macfarlane Trust?

19 A. Yes.

20 Q. And you tell us at paragraph 30 that you had to cancel
21 one of your holidays and lost £700 for that?

22 A. Yes.

23 Q. That your wife was unable to work and lost a salary of
24 £7,500. In paragraph 32 you tell us about expenses you
25 incurred while you were at Edinburgh Royal Infirmary,

1 including an excess of £1,000 on car parking at the
2 hospital.

3 A. It's probably a lot more than that because I think
4 I just took that at -- [REDACTED] was £5 a day and
5 Edinburgh could be anything up to £12 at the time.

6 Q. You obviously had the expense of driving to and from
7 appointments, both in [REDACTED] and in Edinburgh, and you
8 tell us that sometimes for your Edinburgh Royal
9 Infirmary appointments you would have to stay overnight.

10 A. Yes, we always asked for a late appointment but they
11 never ever did it. If we have to be in Edinburgh for
12 10 am, we are leaving [REDACTED] at 6 o'clock in the
13 morning. That means getting up -- bearing in mind
14 I couldn't do much for myself. That's why we had to
15 stay overnight.

16 Q. Is there anything else you would like to say about the
17 effect of your infection with HIV and Hepatitis C on
18 you?

19 A. Well, I mean I could go on all day about that but -- you
20 know, I am lucky that I could do what I did in terms of
21 finance. Not everybody can do that and that's where
22 I think someone needs to sit up and look. Some people
23 are on their own. Some people with family couldn't
24 afford to stay in Edinburgh for six weeks or however
25 long it was, and it's fine for me because I could afford

1 it but there are some people can't, and it's not just
2 me, it's other people, and that's where I think that the
3 people up there just don't appreciate that.

4 I mean, I have got -- it's £40,000-odd this has cost
5 me and if I hadn't been paid, it would have been 80,000.
6 That's hard cash. That's my daughter's money because at
7 the end of the day it's all going to go to her. I'm not
8 motivated by money in any shape or form but there is no
9 way I should be out of pocket for this and, you know, to
10 pay, say, in excess of £1,000 to park a car for
11 a disease that the NHS has given you just beggars
12 belief, it really does. But that's life. You just have
13 to get on with it.

14 Q. Thank you very much for coming here today. Thank you.

15 THE CHAIRMAN: Mr Di Rollo?

16 MR DI ROLLO: Sir, I'm very grateful to my learned friend
17 for her examination.

18 THE CHAIRMAN: Mr Anderson?

19 MR ANDERSON: I have no questions I wish to ask, thank you.

20 MR JOHNSTON: I have none either.

21 THE CHAIRMAN: Thank you very much indeed. It is not easy
22 but you have told a remarkable story.

23 A. Yes.

24 THE CHAIRMAN: Thank you.

25 A. Thank you.

1 PROFESSOR JAMES: Thank you very much.

2 THE CHAIRMAN: So that's all we can do today but I think all

3 I can repeat is that the building will remain open, if

4 that's of any assistance to people. I don't know

5 whether it is. I suspect it's of greater assistance to

6 the people round the back who have a distance to travel,

7 but you are welcome to stay here so long as the weather

8 outside makes it less attractive to you.

9 (12.58 pm)

10 (The Inquiry adjourned until 9.30 am the following day)

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I N D E X

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14 STEPHEN1

15 Questions by MS PATRICK1

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