

Penrose Inquiry

The following transcript is for Day 81 of the Oral Hearings of The Penrose Inquiry, held on 10th January 2012.

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

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Tuesday, 10 January 2012

(9.30 am)

ALEX

Questions by MS PATRICK

THE CHAIRMAN: Good morning. Ms Patrick?

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

Alex, I would like to start by letting you know who everyone is in the room today. Seated on the bench is Lord Penrose. Next to him is Professor James, the medical adviser to the inquiry. Seated next to you and your father is Margaret, who you already know. Coming along the front row here, we have closest to you the two stenographers, who are typing up everything that's said today for the transcript of today's hearing.

Seated next to them is Maria McCann who is the secretary to the Inquiry, and seated next to her is Neil MacFarlane, who is in charge of documents. And as we go through your statements, I will be referring you to parts of your medical records, and those will appear on the screen in front of you.

Seated next to me is Laura Dunlop, senior counsel to the Inquiry, and behind us is Lindsey Robertson, who has been assisting us with this topic. Coming along the other side of the room, we have the lawyers for the core

1 participants. The lawyers closest to me are those
2 representing the patients, relatives and
3 Haemophilia Society.

4 We then have the lawyers for the health boards and
5 the Scottish National Blood Transfusion Service and then
6 seated closest to you, the lawyers for the
7 Scottish Government.

8 You are being known today by the name of "Alex" but
9 that's not your real name. Last year you helpfully
10 provided the Inquiry with a witness statement and I hope
11 that you have a copy of that in front of you.

12 A. I do.

13 Q. And the number of that is WIT0050035. In paragraph 3
14 of that statement, you point out that you were very
15 young when you were infected with the Hepatitis C virus,
16 so some of the information contained in your statement
17 has been provided by your parents, your father on
18 questioning, and from your late mother, [REDACTED]
19 [REDACTED], through reports and notes that she kept
20 during your treatment. Did you have a look at these
21 reports and notes while you were preparing your
22 statement?

23 A. I did, yes. Not necessarily just from those. Obviously
24 I have got recollections from growing up, from -- I did
25 use those as help for reference.

1 Q. Is it fair to say that it was your mother who was most
2 involved in caring for you?

3 A. Yes, obviously my mum and my dad, but my mum took me to
4 the hospital appointments and that kind of -- she did
5 have the biggest bulk, I guess, of the care.

6 Q. And in paragraph 1 you tell us that your date of birth
7 is [REDACTED], so you are you are now 24 years old?

8 A. [REDACTED].

9 Q. [REDACTED]. And you say there that you are unemployed. Is that
10 still the position?

11 A. [REDACTED]

12 Q. [REDACTED]

13 A. [REDACTED]

14 [REDACTED]

15 THE CHAIRMAN: Well, everything is redacted out at the end.
16 So although you tell us now what it is, it won't remain
17 in any final statement.

18 A. Okay.

19 THE CHAIRMAN: As you will appreciate, sometimes it's
20 helpful to know because it tells us more about you.

21 A. Of course, yes.

22 THE CHAIRMAN: Maybe to tell us the type of work rather than
23 precisely where you do it.

24 A. That's okay. I just wanted to confirm. I work in
25 [REDACTED]

1

[REDACTED]

2 MS PATRICK: Yes. Where did you live when you were a child?

3

A. [REDACTED]

4

Q. Did you have any brothers and sisters?

5

A. I did, yes. I had two brothers and one sister. I do

6

still have two brothers and one sister.

7

Q. Where are you in that --

8

A. [REDACTED]

9

Q. [REDACTED]

10

A. Youngest.

11

Q. Youngest, sorry, thank you.

12

You tell us in paragraph 2 of your statement that

13

you have severe haemophilia with less than 1 per cent

14

clotting factor and that you were infected through

15

receiving blood products with the Hepatitis C virus.

16

It's genotype 1A of the virus that you have.

17

A. Yes.

18

Q. Your father also provided the Inquiry with a witness

19

statement and the reference for that is WIT0050001.

20

I thought it would be helpful to look at that to find

21

out about your first admission to hospital in relation

22

to your haemophilia.

23

It's redacted from paragraph 1 but your father is

24

employed as an [REDACTED]. Is that

25

right?

1 FATHER: Well, now I have retired.

2 Q. You are retired now but you were. And where was your
3 work based?

4 A. [REDACTED]

5 Q. Thank you.

6 It's said in paragraph 2 of your father's statement
7 that in October 1986, when you were about six months
8 old, you became very distressed and you were taken by
9 your parents to your GP, who referred you to
10 [REDACTED] Hospital, which I think is now known as
11 [REDACTED] Hospital.

12 I would like to refer you to WIT0050947, which is
13 the letter of referral by the GP to the hospital, dated
14 21 October 1986. It's actually written by a trainee GP
15 and it notes in the second paragraph that your parents
16 noted that your right thigh was swollen on 19 October 19
17 and:

18 "Cried a lot last night. No fever and feeding well
19 (breast fed)."

20 I think that's:

21 "No haematoma. On examination -- pale but lively
22 and playful.

23 "Apyrexial. Not moving his right leg. Distal right
24 thigh and right knee swollen.

25 "Movements on right knee restricted. No other

1 anomaly found.

2 "Osteomyelitis distal femur? Arthritis knee."

3 PROFESSOR JAMES: For the record the word is:

4 "No hypotonia."

5 MS PATRICK: Thank you. Going back to your father's
6 statement, the consultant at the hospital initially
7 thought that the problem was osteomyelitis. So you were
8 treated with medication and detained in hospital. You
9 were then referred to Raigmore Hospital in Inverness.
10 I would like to refer you to WIT0050950. This is the
11 discharge document from --

12 THE CHAIRMAN: Just a minute, there seems to be a problem.
13 Can we just run a little test, please, and see if the
14 new position is helping the stenographers? I think if
15 Alex's father would just say something.

16 MS PATRICK: Thank you very much.

17 This letter that I'm referring you to is a letter
18 from Dr John Macdonald, consultant paediatrician at
19 Raigmore Hospital to your GP, and it's the letter which
20 was sent after your admission there. It's noted in
21 paragraph 1 that you had been:

22 Transferred "to the paediatric unit at Raigmore
23 Hospital on 22 October 1986 for further investigation
24 of the pseudo-paresis of his right leg. There had been
25 a short history of some pain and swelling of the thigh

1 associated with reduced limb movements, otherwise [Alex]
2 had been a healthy baby with no significant past
3 illnesses."

4 In paragraph 2 it's noted the swelling above the
5 right knee and your reluctance to move your right thigh.
6 Paragraph 3 states:

7 "He was anaemic with a haemoglobin of only 8.2
8 grammes and his white count was 22,800 mm³ with
9 40 per cent neutrophils. An x-ray of the right leg
10 showed no abnormalities but a subsequent isotope bone
11 scan showed a diffusely increased uptake with some
12 localisation at the lower end of the right femur
13 suggestive of osteomyelitis.

14 This diagnosis was accepted and treatment
15 with intravenous ampicillin and cloxacillin was started."

16 It then goes on to say that there was some
17 improvement but then it was noted that you were bruising
18 easily. Further down:

19 "A coagulation screen in fact produced undoubted
20 evidence of haemophilia with a prolonged PTT and
21 a Factor VIII level of only 6 per cent indicating
22 moderately severe disease. The haemophilia would appear
23 to be the result of a spontaneous mutation in that the
24 Factor VIII levels in Alex's mother and in his two
25 brothers were perfectly normal."

1 So there was no family history of haemophilia?

2 A. No, I was the first.

3 Q. Did your parents have any knowledge of haemophilia

4 before that time?

5 FATHER: Nothing at all.

6 Q. It was an entirely new thing for you to have to deal

7 with?

8 FATHER: Completely new thing to us.

9 Q. It goes on to say:

10 "Obviously he will require replacement therapy with

11 cryoprecipitate or Factor VIII infusions from time to

12 time following trauma, and before any operative

13 procedure. He is a chubby baby and I can see that there

14 will be quite major technical difficulties in doing this

15 but I hope that Dr Smith will be able to help in the

16 management of this problem. Alex was given an infusion

17 of cryoprecipitate before going home so that his parents

18 could see what was involved, although he did not have

19 any significant bleeding disturbances at that time."

20 So that was obviously your first treatment for

21 haemophilia. Do you remember that?

22 A. I don't remember that.

23 Q. Does your father remember it?

24 FATHER: Yes, I do remember it very well. He was a total of

25 eight days in Raigmore before they discovered he had

1 haemophilia.

2 Q. Yes. So in fact in your statement you say that on the
3 first occasion he was given Factor VIII but it appears
4 from this record that he was given cryoprecipitate.

5 FATHER: We were told it was just a Factor VIII. I didn't
6 realise until I read this statement just now that it had
7 been cryoprecipitate. I thought the first
8 cryoprecipitate he had was in Glasgow. I never even, up
9 until this minute, realised that he ever got
10 cryoprecipitate because it was never discussed with us.

11 Q. I was about to ask you what you were told about the
12 treatment before Alex was given this.

13 FATHER: In Raigmore?

14 Q. In Raigmore, the first time.

15 FATHER: There was no discussion whatsoever. Nothing
16 whatsoever said.

17 THE CHAIRMAN: Before they actually began to infusion the
18 cryoprecipitate, did they tell you what was going to
19 happen?

20 FATHER: No.

21 THE CHAIRMAN: I find it difficult to envisage just what did
22 happen then. Can you help me?

23 FATHER: The best way I can remember it -- it's a pity my
24 late wife isn't here, but I remember the doctor coming
25 into the ward with both of us there. He was a baby.

1 The doctor said, "We have to treat him with Factor VIII.
2 This is the only thing we can do for haemophilia." We
3 don't know what haemophilia was, what it entailed, and
4 he said, "We'll give him a dose of Factor VIII and he
5 has got to be on that probably for the rest of his
6 life," and that was basically it.

7 THE CHAIRMAN: Yes. Which would in fact be absolutely right
8 at that time.

9 FATHER: It should have been right.

10 THE CHAIRMAN: Yes. Factor VIII, of course, is in
11 cryoprecipitate and in the concentrate. It's just
12 Factor VIII is the important thing in each of them.

13 FATHER: Yes.

14 MS PATRICK: Over the page of this letter. At that point it
15 was noted that they were still postulating two separate
16 diagnoses, namely osteomyelitis and haemophilia, and
17 when Alex was discharged home, it was felt advisable to
18 complete the four week course of antibiotic therapy,
19 which was for the osteomyelitis. And the plan was that
20 Alex would return to Dr Macdonald's clinic in December
21 for review.

22 Do you remember if you went back to the hospital in
23 December for review?

24 FATHER: Sorry, you mean Raigmore?

25 Q. Yes.

1 FATHER: No, we never went back to Raigmore. My late wife
2 refused to take Alex back to Raigmore because of the
3 amount of time we were there without any diagnosis.
4 What hurt him most was every time he was being tested or
5 blood was taken off and they were taking him away from
6 her, he was being taken away into another room where we
7 could hear him actually screaming, and she had no
8 control of what he was going through. So then she
9 decided to take him to Glasgow. We were only in
10 Raigmore once ever.

11 Q. Yes, because I know you refer to that in paragraph 4 of
12 your statement when you mention the next time that Alex
13 had to go into hospital due to a bleed. I wonder if we
14 could look, please, at paragraph 4 of your statement,
15 which is ending "0002". Thank you.

16 You tell us a few weeks later the same thing
17 happened again but this time it was Alex's other hip and
18 you were referred to Raigmore, but your wife asked that
19 Alex be transferred to Yorkhill Hospital in Glasgow.
20 You refer there to a letter --

21 A. At that time, from -- remembering what my mum used to
22 say, she always felt like when I was -- it was never
23 explained to her why I was being taken away. It wasn't
24 that it wasn't explained but it wasn't reinforced to
25 her, you know, the importance of getting the actual

1 stuff. It was a case of just I had to go away to
2 another room and get it and then I would come back with
3 bruises on my arm. Obviously I was a baby, so I would
4 have been resisting, but I think in my medical records
5 there was reference to that actual transfer and why my
6 mum was unhappy at the time.

7 Q. Right. I would like to refer you to the letter that in
8 fact you both refer to in your statements, which has
9 a different reference to the one contained in your
10 statement. The reference is WIT0050952. This is
11 a letter to Dr Hann, dated 22 January 1987, from
12 Dr Christine Bryan. It states:

13 "Thank you for agreeing to take over the management
14 of this nine-month old baby boy. He was admitted to
15 [REDACTED] Hospital on 20 January 1987 with swelling of his
16 left thigh. He had previously been admitted
17 in October 1986 with a similar problem affecting the
18 other leg. At that time he was transferred to
19 Raigmore Hospital, where a diagnosis of haemophilia was
20 made. There is no family history. He has been treated
21 with 3 x 6 mls of Factor VIII. Each dose (30 units)
22 given at ..."

23 It's not quite clear that figure, it could be "30":

24 "... eight hourly intervals, the last dose being at
25 10 am on 21 January 1986. There was an initial

1 improvement but today the swelling is more marked. His
2 parents requested that he be reviewed at Yorkhill."

3 Actually, I think this should be "at a hospital other
4 than Raigmore":

5 I understand that they were unhappy about the junior
6 staff there."

7 So that notes that you had been admitted
8 in January 1987 and had received three doses of
9 Factor VIII before being transferred down to
10 Yorkhill Hospital.

11 FATHER: Can I just say, we did actually request
12 Yorkhill Hospital.

13 Q. You did, yes. Do you remember being at the hospital at
14 that time before you were transferred to Yorkhill?

15 FATHER: No, I couldn't go at that time because I was
16 working. I had to look after the other three kids we
17 had, so just my late wife.

18 Q. Do you know if there were any discussions with your wife
19 at that time about Alex receiving treatment?

20 FATHER: No, it was Factor VIII -- that was all we were
21 told: Factor VIII.

22 MS PATRICK: Could I refer you to WIT0050954. This is
23 a letter from Dr Pettigrew at Yorkhill Hospital to the
24 consultant physician at Raigmore Hospital, dated
25 2 February 1987. It starts by thanking him for

1 referring Alex for further investigations and treatment.
2 It narrates the history and then in the third paragraph:
3 "On examination [Alex] had an obvious [patella]
4 haemarthrosis of the left knee, principally in the
5 suprapatellar region. He was also noted to have some
6 bruises at previous venepuncture sites at the right
7 wrist and on the left upper arm. There were no
8 significant findings on examination. He was also seen
9 by Mr Bennett, consultant orthopaedic surgeon, who felt
10 that there was a haemarthrosis of the left knee but that
11 apart from the replacement therapy, no other measures
12 were required. He was given cryoprecipitate 3 units
13 on admission and daily thereafter. The swelling
14 virtually subsided and spontaneous movement in the joint
15 recovered. By 22 January 1987, the haemarthrosis had
16 completely settled and we felt he was ready for
17 discharge. During admission we rechecked his
18 Factor VIII level, which we found to be less than
19 1 per cent. He is thus severely infected and in fact
20 this diagnosis is more in keeping with the occurrence of
21 onto occasions of his spontaneous haemarthrosis in
22 a child of this age."

23 A. The date on there is actually the 28th, not the 22nd.

24 MS PATRICK: Sorry.

25 A. It's the 28 January.

1 MS PATRICK: Sorry, I meant to say that.

2 It's noted over the page that liver function tests
3 were within normal limits. And blood was taken for
4 baseline check of Hepatitis B and HIV status. The
5 results of which are still awaited.

6 Were you at Yorkhill Hospital or once again was your
7 wife there? Do you remember this?

8 FATHER: No, I wasn't there at all at this time.

9 Q. Next paragraph:

10 "We spent a long time with [Alex's mother] explaining
11 the diagnosis of haemophilia and advising her of some of
12 the problems she might face. Fortunately we were also
13 able to introduce her to some parents of older children,
14 who were able to give her more practical advice."

15 Then she was given advice about aspirin,
16 vaccinations and dental treatment. Then how they hoped
17 that you can lead as normal a life as possible with
18 certain restrictions on your activities. Then in the
19 bottom paragraph there:

20 "Although we had treated Alex with cryoprecipitate,
21 which is preferable in young children from the point of
22 view of non-A non-B Hepatitis. We realise that this may
23 not be practical in [REDACTED] and I have told [Alex's
24 mother] that he may in future receive heat-treated
25 Factor VIII concentrate. If you are agreeable, we would

1 be very happy to share the care of this young boy and
2 would be delighted to admit him to Yorkhill Hospital
3 whenever you feel this is necessary."

4 Then the plan is that you will be reviewed there on
5 a four to six-monthly basis.

6 A. Can I just say, at that point, if the doctor was
7 explaining to my mum about my haemophilia, surely they
8 should have explained I was getting tested for non-A
9 non-B and why I might not get heat-treated product
10 because of where I lived, because that seems like that's
11 what it's saying.

12 Q. There is reference in the medical records to non-A non-B
13 testing later. I'll refer you to that.

14 A. Yes.

15 Q. But testing for non-A non-B Hepatitis wouldn't have been
16 possible at this time.

17 A. Just the fact it's referenced in my notes. I'm just
18 interested that it says in my notes -- it references it
19 in my notes.

20 Q. I will refer you to that.

21 A. That's fine.

22 Q. Yes.

23 THE CHAIRMAN: I think, you know, there must always be
24 a temptation for you to try to tell the story your way
25 but it's much more helpful to me and to Professor James

1 if you allow Ms Patrick to ask the questions. That way
2 we can get some logic into it. This is a chance for you
3 to help me understand the realities and sometimes your
4 own preoccupations don't necessarily help. So if you
5 hold back and just let Ms Patrick take the lead, I'm
6 sure it will be fine.

7 MS PATRICK: Thank you. Could I refer back to your father's
8 statement, paragraph 5. It's stated there that it was
9 either January or February 1987 that your mother and
10 father were told by Dr Pettigrew at Yorkhill Hospital,
11 Glasgow -- Sister Murphy was also present -- that the
12 only treatment for haemophilia was Factor VIII but that
13 they would also try cryoprecipitate. Do you remember
14 this?

15 FATHER: Yes, I remember it. It was actually -- if -- my
16 memory might be wrong on the date of that, I'm not quite
17 sure, but I think it was actually February. Alex had a
18 bad mouth bleed. He was breaking his teeth then and he
19 bit his tongue and we had to go to take him to Yorkhill,
20 and he was then given -- if I remember -- if my memory
21 is right, then he was given cryoprecipitate and that's
22 the first we knew -- ever heard about cryoprecipitate.

23 Q. Right. You say there that:

24 "Dr Pettigrew told us that all blood products at
25 this time were heat-treated and were safe."

1 FATHER: We were told -- the first time we went down with
2 Alex to Yorkhill, we were told that all blood products
3 from March 1986 were completely safe and there was no
4 fear of any infection being passed on to Alex through
5 blood products. He wasn't born until April 1986.

6 MS PATRICK: That incident you were referring to you mention
7 in paragraph 6, that there was a time when your son had
8 to be admitted and the medical records show that this
9 was in March 1987, so this is probably the occasion you
10 were talking about.

11 FATHER: I think he was down two or three times with the
12 same problem because I remember one time we went to the
13 hospital at home to get treated because there was so
14 much blood coming out of his mouth and he was actually
15 running -- we couldn't stop him, he was running up and
16 down the corridor. There was a trail of blood on the
17 floor. We had to take him down -- send him to Yorkhill.
18 But the bleeding from his mouth, you know, appeared on
19 a number of occasions.

20 MS PATRICK: Yes. If I refer you to WIT0050957, this is
21 the referral from Alex's GP to Dr Pettigrew, noting that
22 he has arranged Alex's admission for tomorrow with
23 Dr Gibson. The date of this letter is 23 March 1987 and
24 it notes that he had fallen and cut his tongue on his
25 teeth and despite Factor VIII intravenously on two

1 occasions in the past week, it appeared that he needed
2 more intensive therapy for this to heal.

3 Could I refer you to WIT0050959, which is a letter
4 from Dr Pettigrew to Alex's GP, dated 23 April 1987.
5 This is in respect of this admission and it notes in the
6 bottom of the second paragraph that Alex was given two
7 bags of cryoprecipitate on admission.

8 In the third paragraph it says that they took the
9 opportunity to give him his third triple vaccine while
10 he was on the ward. And it's noted over the page that
11 at that time Alex was seen by the physiotherapist and
12 given a protective helmet and that you and your wife
13 were seen by Mrs Leach, the department social worker.

14 Do you remember seeing Mrs Leach?

15 FATHER: Yes, I absolutely do.

16 Q. Yes. What were the discussions with her?

17 FATHER: Mrs Leach, she was only explained what protective
18 gear you get for Alex: knee pads, elbow pads, helmet,
19 but he wouldn't wear the helmet. He was stubborn.

20 Sorry.

21 But that was basically all we had to do with
22 Mrs Leach, just the protective gear that was supplied.

23 Q. Yes. In the next paragraph -- it has been deleted there
24 but I think it was noted that you were actually staying
25 in Glasgow for a week's holiday and fortunately you and

1 your wife were able to attend a cheese and wine party
2 which was organised by the haemophilia parents:

3 "I hope that they found it useful meeting other
4 parents as I know that they are under considerable
5 stress at the moment."

6 FATHER: Yes, that was arranged by the West of Scotland
7 parents group, whatever. I can't remember what they
8 were called.

9 Q. Did you find that helpful?

10 FATHER: We found it very, very helpful but it was
11 completely outwith the hospital altogether.

12 Q. It refers there to the stress that you were under. Was
13 this due to Alex's diagnosis with haemophilia?

14 FATHER: Yes, and the situation we were in. We were so
15 isolated, away from other people with the same problem.
16 We had nobody in our area with the same problem and
17 there was nobody we could discuss it with. But we had
18 to wait for Alex's appointment in Glasgow to get down
19 there to meet other parents and find out exactly what
20 was going on. It was a very, very stressful time.
21 I think a lot of that caused us -- his mother's illness,
22 the stress that she went through over years.

23 THE CHAIRMAN: I wonder whether I could ask one or two
24 questions about that. The remoteness is obviously
25 interesting in Scotland and you are presenting quite an

1 example of it. Did the position ever change? Did you
2 ever have contact with other families affected by
3 haemophilia [REDACTED]?

4 FATHER: There was only two other families in [REDACTED]
5 that had anybody -- well, had a connection with
6 haemophilia. One, if I remember the age right, he
7 was -- was he an eighty-year old? I think he was about
8 eighty years old when we first got in touch with him.
9 The other family, they had lost a son previously --
10 previous to Alex being born and they didn't want to
11 discuss anything.

12 THE CHAIRMAN: How did you get information about the other
13 two families?

14 FATHER: Through the doctors, through our doctor at home,
15 our family GP.

16 THE CHAIRMAN: Had you raised with the family GP this
17 problem of isolation?

18 FATHER: We spoke about it. We thought about once of moving
19 to Glasgow, to be nearer Yorkhill obviously, where he
20 was getting his treatment.

21 THE CHAIRMAN: I suppose the doctor would make contact with
22 the other families to see if they wanted contact with
23 you.

24 FATHER: Yes.

25 THE CHAIRMAN: He couldn't give you details before.

1 FATHER: The 87-year old guy -- well, 80-year old, I should
2 say -- he was very, very forthcoming. He didn't even
3 know he had haemophilia until he was over 40 years of
4 age.

5 A. It's worth pointing out they both had mild haemophilia.

6 FATHER: Yes, that's right. It was mild haemophilia.

7 A. They were having a different experience from having
8 severe haemophilia.

9 THE CHAIRMAN: I don't want to complicate this too much.
10 I was really trying to get a feel for the implications
11 of living in a remote community, and one of them would
12 be that you wouldn't have ready contact with other
13 families with remotely similar problems.

14 FATHER: That's right, yes.

15 THE CHAIRMAN: But you did get some help, so far as the GP
16 could do, in making contact.

17 FATHER: Again, like I say, they didn't want to be in touch
18 with anybody. They wanted to keep it to themselves.
19 There was a stigma about it at the time. We were trying
20 to open out but they were trying to hold back.

21 THE CHAIRMAN: Yes. Of course, each of them would have
22 lived with the problem for a long time by this stage.

23 FATHER: Yes, exactly.

24 THE CHAIRMAN: Yes, thank you.

25 MS PATRICK: Just following on from that, was there such

1 a thing as a [REDACTED] group for people with
2 haemophilia?

3 FATHER: I couldn't answer that one, I couldn't answer that.

4 [REDACTED]

5 [REDACTED]

6 Q. And you didn't --

7 FATHER: Well, it was easier for us coming to Glasgow
8 anyway, meeting the parents in Glasgow.

9 Q. And the impact of having to travel to these clinic
10 appointments on your family life; what was that like?

11 FATHER: It was quite hard because if the two of us
12 travelled down with Alex to Glasgow, we had to get
13 somebody to look after the other children, or if it was
14 just a three-monthly or four-monthly appointment,
15 whatever it was, either one of us would come down and
16 the other would stay at home because we had another
17 three kids, and it was very, very difficult.

18 Q. How long would it take you to go to an appointment?

19 FATHER: [REDACTED]

20 Q. Could you do it in a day?

21 FATHER: Very, very seldom. If you managed to [REDACTED]

22 [REDACTED]

23 [REDACTED], and you got straight through
24 your appointment -- but you all know what hospitals are
25 like, you sit there for ages waiting for your turn to

1 come round. So you could actually miss the late
2 afternoon [REDACTED] home and then you had accommodation and
3 get back the next day, which I'm afraid my son here
4 didn't enjoy very much staying down in Glasgow. [REDACTED]
5 [REDACTED]

6 THE CHAIRMAN: [REDACTED]

7 MS PATRICK: You tell us in paragraph 7 of your statement --

8 THE CHAIRMAN: Sorry, whose statement are we on now?

9 MS PATRICK: Sorry, there is one other point I need to
10 clarify: the two people locally with haemophilia, did
11 you say that one was 87?

12 FATHER: Well, he was 80 anyway, because I think he died at
13 87. I was getting a wee bit confused. He died at 87.
14 He was the oldest living haemophiliac in Scotland.
15 I think he was actually in the UK. It is just for the
16 record.

17 Q. Just for the record. Thank you.

18 Going back to your father's statement, paragraph 7,
19 after these admissions to hospital, the position was
20 that you generally attended your GP for treatment in the
21 first instance for bleeds, and you attended clinic
22 appointments at Yorkhill?

23 FATHER: Yes.

24 MS PATRICK: You tell us in paragraph 8 of your statement
25 that you went to Yorkhill every three months for

1 check-ups and during these check-ups a blood test would
2 be taken:

3 "We were told that this was to check [Alex's] factor
4 levels and liver functions."

5 FATHER: Well, as far as liver functions were -- we weren't
6 quite sure what it was all about. It was never
7 explained to us.

8 Q. So were you actually told that the blood tests were
9 being used to check factor levels and liver functions?

10 FATHER: Just factor levels.

11 Q. Factor levels?

12 FATHER: Factor levels in his blood. What we were told in
13 Glasgow was that he had to do these blood tests every
14 appointment, every -- was it four months or whatever --
15 I can't -- three months, whatever it was. And they were
16 also doing a liver test, which was quite normal, they
17 told us.

18 Q. What did you understand the liver tests were for?

19 FATHER: We didn't know. Nobody ever explained.

20 Q. Did you ask?

21 FATHER: I don't know if I'm jumping the gun by going to
22 non-A non-B. When that came up, even then nobody
23 explained what it was all about.

24 Q. Could I refer you to WIT0050973? Which is a letter
25 dated 30 June 1989 from J Kelt, clinical assistant in

1 the haematology department, to Alex's GP. It notes that
2 Alex had attended two weeks previously for routine
3 review. If we scroll down to the bottom of the first
4 paragraph, we will see from about the fifth line from
5 the bottom:

6 "Some routine bloods were performed for virology,
7 biochemistry and haematology. His biochemistry screen
8 has returned showing a moderate elevation of his liver
9 enzymes, his AST is 208 and his ALT 412, bilirubin
10 is normal, as is his Albumin."

11 These blood test results, were they something that
12 was discussed with you?

13 FATHER: Well, all we were told was that he was being tested
14 for non-A non-B, and I remember one specific time, I
15 asked, "What is non-A non-B?" "It is just a test that
16 we do," that was the answer I got. We didn't even know
17 what "non-A non-B" meant, because it was never explained
18 to us.

19 Q. You tell us in paragraph 9 of your statement that you
20 were told that everyone with haemophilia was being
21 tested for this.

22 FATHER: For non-A non-B, yes.

23 Q. But you say that you weren't given the results of the
24 tests for non-A non-B Hepatitis.

25 FATHER: No.

1 Q. Could I refer you to WIT0050962, which is
2 a handwritten nursing note dated, I think,
3 8 August 1989, noting:
4 "Returned for blood results. LFTs improved. Seen
5 by Dr Chalmers."
6 It notes:
7 "Bruise on right buttock and small red swelling over
8 HB ..."
9 I think that is Hepatitis B:
10 "... injection site. Neither required treatment.
11 Bloods for non-A non-B to Edinburgh. LFTs repeated.
12 See in four months."
13 Do you remember that appointment?
14 FATHER: No, I can't -- I can't say I was there at the time.
15 I might have been but I just can't ... I remember the
16 signature there, Ms Murphy. I remember her very well.
17 Q. Yes. If we look at WIT0050977, this is a letter from
18 Dr Gibson, consultant haematologist, to Alex's GP, dated
19 29 November 1989, after he has been seen for review at
20 the haemophilia clinic on 24 November 1989. If we go
21 over the page, it's noted in the fourth line down:
22 "As you know, he has been shown to have elevated
23 transaminases for many months now. When these were last
24 repeated in August, they had virtually returned to
25 normal. Blood was sent for HCV antibody, a new marker

1 for non-A non-B Hepatitis, and like many of our
2 haemophiliacs, [Alex] is positive. This explains his
3 slightly deranged liver function and will have resulted
4 from either cryoprecipitate or Factor VIII concentrate
5 therapy. Over the last year, when we have been
6 monitoring [Alex] more carefully, his liver function
7 appears to be improving but this may well alternate. Blood
8 was taken to check his liver function test at this clinic
9 visit and the results will be appended. In the meantime
10 I plan to see [Alex] in four months' time but will be
11 happy to see him as an emergency if the need arises
12 sooner."

13 So here there is mention of an antibody to the
14 Hepatitis C virus. Do you remember that being discussed
15 with you?

16 FATHER: Never.

17 THE CHAIRMAN: Did you go and see the GP after these visits
18 to Yorkhill?

19 FATHER: Well, we always had a GP. We always went to the GP
20 for his Factor VIII because before we started home
21 treatment, we always went to the GP. But the GP never
22 discussed anything with us really.

23 THE CHAIRMAN: He clearly has a lot of information from the
24 hospital, as you can see. You say he never spoke to you
25 about that at all?

1 FATHER: No. The only information that we had was when we
2 attended appointments in Glasgow. The few things they
3 did discuss with us are there. That's the only thing we
4 ever took home from discussions between us.

5 THE CHAIRMAN: Sorry?

6 FATHER: The only points we ever discussed between us at
7 home were the points that were taken up in Glasgow.

8 THE CHAIRMAN: Did you ever pick up Haemophilia Society
9 leaflets and things like that in Glasgow?

10 FATHER: Yes.

11 THE CHAIRMAN: All the time, I suppose.

12 FATHER: That's more or less where we found out all the
13 information, through leaflets.

14 THE CHAIRMAN: Let's just see where we were because I have
15 lost it just a little myself.

16 FATHER: Sorry.

17 THE CHAIRMAN: Yes, thank you, Ms Patrick.

18 MS PATRICK: You said that you remembered Chris Murphy very
19 well.

20 FATHER: Oh, yes.

21 Q. How regularly did you see her?

22 FATHER: We always saw her at the three-monthly
23 appointments.

24 Q. What role did she play in Alex's treatment?

25 FATHER: She was the sister in -- I don't know, was it the

1 we were just referred on to the doctor for his blood
2 tests or whatever. So it was just like a conveyor belt
3 along the line.

4 Q. How long would you see her for each time you went?

5 FATHER: Maybe 10 minutes, 15 minutes at the most.

6 Q. Did you feel you could ask her any questions you had?

7 FATHER: Yes, very much so.

8 Q. And was she a good source of information for you?

9 FATHER: Yes, she was very helpful as regards haemophilia.

10 Q. Thank you. Before the break we were also looking at the
11 letter of 29 April 1989, WIT0050977 where it was noted
12 that blood was sent for HCV antibody. Alex, I wanted to
13 refer you to a paragraph of your statement. Your father
14 has told us that he does not remember being given the
15 results of the tests for non-A non-B Hepatitis. But in
16 paragraph 10 of your statement, which is WIT0050037,
17 you tell us that your parents were informed about your
18 infection during a routine appointment in November 1989,
19 which would tend to tally with this letter:

20 "At that time it was referred to as non-A non-B
21 Hepatitis. They were taken into a consulting room at
22 Yorkhill Hospital and told by Dr Pettigrew that it could
23 have been as a result of either cryoprecipitate or
24 Factor VIII treatment."

25 What's that based on?

1 A. It must either be based on notes I had from my mum or
2 possibly a letter I had somewhere.

3 Q. Was that your understanding from --

4 A. It seems I have written that in some detail. So
5 I imagine -- I must have had some reference to get to
6 that.

7 THE CHAIRMAN: It doesn't look like what you would just
8 remember without prompting, does it?

9 A. I don't really have a good memory of my third and fourth
10 years.

11 MS PATRICK: And you were three years old at the time.

12 THE CHAIRMAN: Is this the sort of material in your mum's
13 notes, quite detailed?

14 A. Yes, they were quite detailed. I think you have a copy
15 of them.

16 THE CHAIRMAN: I don't do my own homework, Alex, I wait to
17 see what I'm told.

18 MS PATRICK: So, does that ring any bells with you?

19 FATHER: Well, I don't actually remember the date exactly
20 but I remember being taken in and being told of this
21 non-A non-B test that was being done, and it was to do
22 with treatment he was getting, but every haemophilia was
23 getting this test, the non-A non-B test. We were never
24 told exactly what the non-A non-B -- what it actually
25 stood for.

1 Q. This is obviously saying that apparently you were
2 informed that Alex was infected with non-A non-B
3 Hepatitis but you have told us that you weren't aware of
4 the results of any non-A non-B --

5 A. No, we weren't aware of any results -- well, I can't
6 remember being -- in November 1989 being told. He was
7 only three years old.

8 Q. Yes.

9 FATHER: If I'm allowed to take it forward, I think he was
10 about eight years old when we knew he had hepatitis.

11 Q. Yes, I was going to come on to what you say in your
12 statement about when you find out. Alex started
13 prophylactic treatment in about October 1990. Does that
14 sound about right? When he was about four years old?

15 A. Probably, yes, when he was four years old.

16 Q. And home therapy treatment in about August 1992?

17 A. I can't exactly remember when his home treatment
18 started.

19 Q. Could that be about right?

20 FATHER: We were back and forward from Yorkhill for quite
21 a time learning how to do it.

22 Q. How did you find the prophylactic treatment?

23 A. Me personally? I hated it. I hated having to get
24 injections. I understood why I had to get them but it
25 just wasn't very nice having to have a needle stuck into

1 your arm.

2 Q. Who gave you your injections?

3 A. To begin with it was my local GP and also, when I went

4 down to Glasgow, I would get treatment if I needed.

5 Q. Once you started home treatment, who gave you --

6 A. It was mainly my mum but occasionally I would go to

7 the GP to get it.

8 FATHER: Sometimes his mum couldn't -- directly into the

9 vein or it was a struggle, and he was getting very upset

10 so then we had to take him to the GP.

11 Q. It can't have been an easy thing for a mother to do to

12 a reluctant young child?

13 FATHER: Oh, it wasn't easy. It wasn't easy for the family.

14 Q. No. And the hospital continued to monitor your

15 condition. If we look at WIT0050979, this is a letter

16 from Dr Gibson to your GP, dated 10 April 1990, which

17 records that you were seen at the clinic recently. It

18 states in the second paragraph:

19 "As you know, we have been seeing [Alex] more often

20 because of an elevation of his liver transaminases."

21 Were you aware that Alex was being seen more often

22 because of this?

23 FATHER: No. Just his normal routine appointment.

24 Q. It notes:

25 "Since we last saw him he has had no episodes of

1 jaundice or abdominal pain, and at clinic his liver was
2 not palpable. At the end of last year his liver
3 function test had returned to normal but of course these
4 may well fluctuate."

5 Further blood tests are taken and the results of
6 these are over the next page, 0980. AST of 62 and
7 I think the ALT result was not available.

8 If we look at WIT0050981, this is a positive
9 antibody test in respect of the Hepatitis C virus, dated
10 20 April 1990, meaning that Alex had been exposed to the
11 virus but didn't necessarily have it. I'm going to come
12 on to when you found out that Alex had the Hepatitis C
13 virus, which in your statement you say was between 1992
14 and 1994.

15 FATHER: Well, it was about maybe four weeks before he
16 started to get his interferon injections that we were
17 told he had Hepatitis C.

18 A. Are you sure?

19 FATHER: What?

20 A. Are you certain?

21 FATHER: I'm not quite sure of the times.

22 Q. Fairly close. In your statement you say it was about
23 a year after finding out that Alex --

24 FATHER: It could have been.

25 Q. So since he started treatment in 1994, you don't think

1 you were made aware of that positive antibody test
2 in April 1990? Which is four years earlier, before
3 treatment --

4 FATHER: We knew he was getting a non-A non-B test but we
5 didn't know it was for Hepatitis C. What amazes me
6 is -- looking at these medical records -- is that our GP
7 and doctors in Yorkhill knew he had Hepatitis C but we
8 were never, ever told. You know, the NHS let us down
9 badly, as a family. I'm shocked. I'm absolutely
10 shocked about it.

11 Q. If we could refer to a further letter from Dr Gibson to
12 your GP, dated 8 October 1990, this follows a review at
13 the clinic on Friday, 5 October 1990. Actually, could
14 we go over the page to 0984? It records in the last
15 paragraph --

16 THE CHAIRMAN: Sorry, can I just be clear about that
17 numbering? The page before is 0941 and the following
18 page is 0984.

19 MS PATRICK: Sorry, my number is 0983.

20 THE CHAIRMAN: I understand that this is part of a great
21 bundle of medical records and the order doesn't
22 necessarily represent reality, but this is the second
23 page of that letter.

24 MS PATRICK: Yes.

25 THE CHAIRMAN: Right.

1 MS PATRICK: Sorry, if we go over to the second page, the
2 last paragraph:

3 "As you know, he is positive for antibody to
4 Hepatitis C and has had deranged liver function tests in
5 the past. When these were repeated in April, his AST
6 was mildly elevated at 62 units per litre and
7 unfortunately his ALT was not done. Bilirubin was
8 normal. His liver function tests were again checked and
9 I will append the results."

10 And they are noted below:

11 "At his next visit to Glasgow I will arrange for him
12 to have an ultrasound of his liver."

13 The records show that in April 1991 Alex underwent
14 a liver ultrasound, and the record of this is
15 WIT0050986. Do you remember Alex having an ultrasound
16 of his abdomen?

17 FATHER: I wasn't in Glasgow at the time. I remember
18 hearing about it. I was working away from home at the
19 time.

20 Q. Sorry, this is a letter from Dr Gibson to the GP, dated
21 8 April 1991. If we go to the bottom, it's noted at the
22 very end that:

23 "An abdominal ultrasound was done at this clinic
24 visit in view of his Hepatitis C and I will append the
25 result."

1 And it's noted there: "normal results."

2 There are further antibody tests for the Hepatitis C
3 virus, dated 19 October 1990. The reference for that is
4 WIT0050985, but I don't propose to look at that.
5 There is a further one in April 1991, WIT0050988. If
6 I could refer you, please, to WIT0050991, this is
7 a letter from Dr Gibson to Alex's GP, dated
8 13 April 1992. It records in the first paragraph that
9 it's a year since he was last seen in Glasgow. It's
10 noted at the bottom of the first paragraph:

11 "His general health appears good, although he has
12 had a number of upper respiratory tract infections." The
13 findings on examination are noted in paragraph 2.

14 Going to the next paragraph, the last line:

15 "His liver function tests were again checked and his
16 AST is raised at 91 units per litre and his ALT at 66
17 units per litre. I wonder if I could ask you to repeat
18 his liver tests in about three months' time and forward
19 the results. A number of haemophiliacs are now
20 receiving interferon in an attempt to clear the virus.
21 It may be that [Alex] should be considered for this
22 approach. It is therefore important to document the
23 degree of liver derangement more closely. I did not
24 discuss interferon treatment in any depths with [Alex's
25 mother], other than to mention that some haemophiliacs

1 were receiving this treatment if their liver problem is
2 severe enough and that over the next six months or so,
3 we should decide if [Alex] would be a suitable candidate."

4 There is a test result following this appointment,
5 WIT0050993, and this is dated 21 April 1992:

6 "Positive for antibody to Hepatitis C virus.
7 Confirmed by RIBA-2."

8 And the date of the specimen that that test was
9 carried out on was dated 10 April 1992.

10 Returning to your father's statement, paragraph 11,
11 which is at 0003, you state:

12 "My son must have been about six or seven years of
13 age (sometime between 1992 and 1994) when, during
14 a routine appointment at Yorkhill Hospital Glasgow,
15 Dr Pettigrew or Dr Chalmers told us that [Alex] had
16 Hepatitis C. We were not aware that [Alex] was being
17 tested for Hepatitis C. The doctor explained to us
18 about Hepatitis A and Hepatitis B, and said that there
19 was now a new hepatitis and it was Hepatitis C. We were
20 not told anything about the long-term implications. We
21 were told that there was no treatment at this time for
22 Hepatitis C but that the medical world was working on
23 treatment. [Alex] was not told at this time he had
24 Hepatitis C. We were not told anything about secondary
25 infection. Neither [Alex], my wife, nor I were offered

1 any counselling. No one suggested at this time as to
2 how [Alex] had contracted Hepatitis C."

3 So, from what you said earlier, it seems likely
4 that, if your son started treatment for Hepatitis C in
5 1994, you think that you found out about it within
6 a year of that?

7 FATHER: Roughly, probably.

8 Q. You think?

9 A. I'm not sure. My memory fails me.

10 Q. Were you and your wife both at the appointment when you
11 found out that Alex had acquired the Hepatitis C virus?

12 FATHER: No, it was just my late wife.

13 Q. And you have stated there that:

14 "We were not aware that Alex was being tested for
15 the Hepatitis C virus."

16 FATHER: As far as we were concerned it was non-A non-B, all
17 these years. We didn't know what it was all about.

18 Q. So was the first mention to you of the Hepatitis C virus
19 when you found out that Alex had acquired it?

20 FATHER: Yes, when my late wife was down with him at his
21 appointment. That's what I mentioned earlier. I can't
22 believe all these doctors, GPs and doctors in the
23 hospital knew about it and we were never told, until we
24 were told that he had Hepatitis C.

25 Q. So I take it from that that your position is that you

1 didn't agree to Alex being tested for the virus?

2 FATHER: Oh no, it was a common thing as far as we knew,
3 that this non-A non-B test was for all haemophiliacs.
4 But not for Hepatitis C.

5 Q. No. So what would you say to the suggestion that all
6 parents of children agreed to their children being
7 tested for the Hepatitis C virus?

8 FATHER: Well, I cannot say really. Obviously we would have
9 asked for him to be tested for Hepatitis C at a younger
10 age but we were told that all blood products were safe
11 from March 1986 before he was born. There should have
12 been no fear of infection in any way whatsoever.

13 A. I think, from my mum's notes and what she told me, there
14 was always so much information flying around that it was
15 hard for her, and probably my dad, but he might not
16 agree, for them to decipher what to take on board and
17 what -- they were struggling to come to terms with
18 haemophilia because it was never in the family, and all
19 the implications surrounding that, let alone this other
20 thing that I was being tested for. Non-A non-B was
21 nothing and nothing. It was hard for them to
22 understand -- my mum anyway -- to understand what --

23 FATHER: Most of the time I was away from home and she had
24 to do a lot on her own.

25 A. Which is why she took so many notes, because she had

1 to relay the information back to my dad.

2 FATHER: Whenever I come home. If it wasn't over the phone,
3 she had to wait for my time off when I got home.

4 A. She was always paranoid that she would forget things, so
5 she would write down questions that she had, and thoughts
6 and feelings.

7 FATHER: One thing she used to do was write the questions
8 she was going to ask when she reached at Yorkhill. Ask
9 the doctors there. She used to write it down so that
10 she always had the right things written down. And
11 I think probably Alex still has got that on record, his
12 private records.

13 Q. I take it she came home and told you that she had been
14 told that Alex had Hepatitis C virus?

15 FATHER: Yes.

16 Q. Can you remember what she said to you about what that
17 meant?

18 FATHER: I can't really remember but I remember her being
19 very upset, both of us. There was no explanation
20 whatsoever. He has just got Hepatitis C, you know?

21 Q. So do you feel that she was given clear advice about the
22 effect of the virus?

23 FATHER: Sorry?

24 Q. Do you feel that she was given clear advice about the
25 effect of the virus at the time --

1 FATHER: No, there was no clear advice whatsoever. I know
2 that for a fact. We didn't even know what Hepatitis C
3 was. There was no explanation, nothing.

4 Q. So what did you think that it meant for Alex?

5 FATHER: Well, it took a long time to sink in, what was
6 going to happen, and then our own GP explained what
7 Hepatitis C meant, what the implications were, the
8 long-term, and it wasn't nice. It wasn't nice.

9 Q. Did you initiate an appointment to see your GP to
10 discuss the Hepatitis C virus? Or did that happen --

11 FATHER: The GP we had was very friendly with us and he was
12 very, very good to us over the years since he started
13 coming first to treat him with Factor VIII. We could
14 call him any time. He was a family friend as well as
15 a GP. So he would come to sit with us and explain to
16 us.

17 Q. So is that something that you did when you found out
18 that Alex had the Hepatitis C virus, you contacted him?

19 FATHER: Yes, it probably was. I can't remember at the
20 time.

21 Q. You said that you didn't tell Alex at that time due to
22 his age. Were you given advice about that from the
23 hospital?

24 FATHER: Well, I think part of it was for the stigma
25 involved of being -- in a small community -- and being

1 the only haemophiliac in, what, [REDACTED] people, and the
2 stigma involved in it, we didn't want to feel as if he
3 was on the outside of the fence and all the other kids
4 on the other side.

5 A. It was hard enough to have haemophilia, let alone
6 something else as well.

7 FATHER: Sorry. A lot of people, even to this day, in
8 our -- in our village at home, which is not that big --
9 that knows that Alex has Hepatitis C -- because it has
10 been kept very, very secret, within the family, because
11 we don't want -- it's just -- I don't know. Just the
12 way that we are treated and what happened, when it
13 shouldn't have. It should never have happened. It
14 should never, ever, ever have happened.

15 Q. So who, if anybody, did you tell about Alex's diagnosis
16 with Hepatitis C?

17 FATHER: Well, the immediate family, his brothers and
18 sister, and even some of his aunties, his mum's sisters,
19 they were never told. Very, very few people within the
20 family circle knew about it. Even to this day they
21 don't know about it.

22 A. Round about that time -- I always knew I had
23 Hepatitis C. I kind of -- there was never one point
24 where I was sat down and told, it was always just kind
25 of there. I had haemophilia, I had Hepatitis C. One

1 was for blood, one was for liver. I knew that they both
2 weren't very good but I just had it.

3 Q. I think, your father says in his statement, that you
4 were told in about 1994 but your impression is that you
5 just --

6 A. I think that was more --

7 Q. -- remember being aware of having both?

8 A. I think that would more have been explanation of my
9 treatment, of that Interferon. My mind started asking
10 questions. I remember on a plane journey to the
11 hospital, I asked my mum what was Hepatitis C and she
12 said, "It's like a scar on the liver," and I said, "Why
13 do I have to get treatment for it?" and she said,
14 "Because it's just not very good. It's not very good
15 that you have it." That was enough for me, that I had
16 something I shouldn't really have so I need to get
17 better, and in my head -- at that stage in my life, that
18 was enough for me to ...

19 Q. Were you given help in telling Alex about having
20 Hepatitis C?

21 FATHER: Not one iota of help. From any line, in any way.
22 From doctors, nurses, anybody. Just bluntly told us he
23 has got Hepatitis C; in other words, "Get on with it".

24 Q. And you say in your statement that none of you were
25 offered any counselling --

1 FATHER: No.

2 Q. And I think you state later on in your statement, in
3 paragraph 16, that neither you nor your wife were
4 offered testing for the virus.

5 FATHER: No. The only testing we ever had was his two
6 brothers were tested for haemophilia, for Factor VIII in
7 Yorkhill, whatever, when he was very, very young.

8 Q. Moving on to Alex starting school, which was
9 in August 1991, we don't need to look at it but you say
10 in paragraph 14 that Alex had a wheelchair to try and
11 prevent him from knocking himself and having so many
12 bleeds.

13 FATHER: Yes, we always had a wheelchair. We had
14 a wheelchair at home but they also had one in the school
15 and they also had a stair lift because some parts of the
16 school were up the stairs, and the school actually got
17 stair climbers.

18 Q. It's noted in a document, which we don't need to look
19 at, WIT0050989, which is the referral of Alex to the
20 wheelchair clinic, that he was having recurrent bleeds,
21 particularly in the ankles and knees, which could occur
22 once or twice a week, and you would be unable to weight
23 bear for several days. So he has to be carried
24 everywhere by his mother, and as a result he missed
25 a considerable amount of schooling.

1 So in the early days did you miss a lot of your
2 schooling, Alex?

3 A. I did, yes. It was quite hard for me at the time
4 because, as well as having haemophilia, I was in
5 a wheelchair, so it wasn't very cool to go to school in
6 a wheelchair. I just hated it because I would have to
7 get pushed around as well and it wasn't very pleasant.

8 Q. Did you have to stay in the wheelchair all day?

9 A. Yes, pretty much, yes. If I had a knee bleed it
10 wouldn't be sensible for me to move it. So I would be
11 in it all day.

12 Q. Then if I could refer you to WIT0050994, this is
13 moving on to the issue of you starting treatment in
14 respect of the Hepatitis C virus. It's a letter from
15 Dr Gibson to your GP, dated 18 August 1992. Could we
16 move over to the second page? Just in passing, in the
17 first paragraph it's mentioning your mother learning to
18 give you your treatment on a home therapy programme, and
19 then the next paragraph:

20 "You will remember that [Alex] is positive for
21 Hepatitis C and has had deranged liver function tests in
22 the past. When checked at clinic, they were improved to
23 AST of 60 and ALT of 66. However, I would like to
24 continue monitoring his liver transaminases but perhaps
25 wait until the end of the year to decide if interferon

1 therapy would be appropriate."

2 In fact, it appears from the medical records that
3 treatment with interferon was not discussed with you
4 until July 1993. If we could refer you to WIT0051002,
5 this is a letter once again from Dr Gibson to Alex's GP,
6 dated 6 July 1993. It's noted in the first paragraph
7 that you are now on a home treatment programme with your
8 mother injecting your Factor VIII concentrate. It is
9 noted in the second paragraph that you are coping well
10 in primary 3. You have had no episodes of jaundice,
11 although you are known to be Hepatitis C
12 antibody-positive:

13 Findings on examination are in the next paragraph
14 and if we go over the page, it's noted:

15 "His liver function tests remain elevated, in
16 keeping with Hepatitis C chronicity. Interferon is now
17 being used in some haemophilia patients in the hope of
18 clearing virus, although it has not been particularly
19 successful. It requires to be given three times weekly
20 subcutaneously and this seems quite an undertaking in
21 [Alex]. However, when results of pilot studies become
22 available, it may seem appropriate. I have discussed
23 the issue in a preliminary fashion with ..."

24 I wonder if this is with your mother. Do you
25 remember this appointment?

1 FATHER: No, I cannot, I'm sorry but I think it must be.

2 Q. "... and will decide when he next attends clinic in
3 three months' time."

4 A. I can remember these appointments. I remember going to
5 them and my mum, she always, I think -- I don't know how
6 she found out about interferon but she decided that she
7 didn't want me on it, because obviously it would help
8 me. But there was always a tension, I found, at my
9 consultant's appointments because my mum would want me
10 on it. She was unsure of the risks and the benefits of
11 it.

12 Q. Did she have discussions with the doctor about these?

13 A. Yes. I was never fully involved in them but I was
14 always aware of them.

15 THE CHAIRMAN: Ms Patrick, there is an internal
16 contradiction in the big answer, which I think you might
17 look at again. You see in lines 3 and 4, what Alex is
18 recorded as saying is that "she decided that she didn't
19 want me on it" and then in line 22, "there was tension
20 because my mum would want me on it". I think I would
21 like to be absolutely clear which one is Alex's
22 evidence.

23 A. I think my mum was apprehensive about the benefits and
24 the negatives of it.

25 THE CHAIRMAN: Yes.

1 A. But she did want me on it. She wanted me on it but she
2 was unsure.

3 THE CHAIRMAN: I see, yes. She wanted you to have the
4 benefit of the treatment but she really needed help in
5 understanding what it was all about.

6 A. I don't think she did fully understand it.

7 THE CHAIRMAN: No.

8 A. Just judging by -- because she had questions in her
9 notebook asking things like, "What are the benefits?
10 Will this harm him?"

11 FATHER: It was never explained what the benefits were and
12 what the implications were of getting interferon.

13 MS PATRICK: I would like to refer you next to WIT0051006,
14 which is a letter dated 17 January 1994 from Dr Gibson
15 to Alex's GP, and this is about Alex starting treatment
16 with interferon in the Easter holidays. You will see in
17 the third paragraph it's noted:

18 "I feel there is now enough evidence to suggest
19 trying to clear the virus with interferon and have
20 arranged for [Alex] to spend a two-week period in Glasgow
21 during his Easter holidays so this treatment can be
22 started. Because of the frequent injections that this
23 will require, I have not reinstated prophylactic therapy
24 in the hope that compliance with interferon will be
25 better."

1 So that suggests that prophylactic treatment had
2 been stopped for a while. Do you remember that?

3 A. Yes, I did -- I was always quite resistant in getting my
4 prophylactic treatment. I took it but I never maybe
5 took as much of it as --

6 Q. You didn't like it?

7 A. I never took as much of it as I should have.

8 FATHER: It was a struggle. You can understand in a
9 seven-year old boy.

10 THE CHAIRMAN: Could you keep your voice up.

11 FATHER: Sorry. It's very difficult with a seven-year old
12 lad to get him to take all his medication, whether it's
13 intravenous or by tablet or medicine form, you know?

14 MS PATRICK: I'm sure it's very difficult for the parents
15 too.

16 FATHER: It was very difficult for the parents too.

17 Q. If we look at WIT0051010, we will see that Alex's
18 treatment was given as part of a study entitled
19 "A prospective study of the efficacy of human Alpha
20 interferon in the treatment of chronic liver disease and
21 haemophilia."

22 And this is a consent form, which I think is signed,
23 is it, by you or your wife?

24 FATHER: It was probably my wife who signed it. I can't
25 remember signing that at all.

1 Q. Right. It notes that:
2 "The nature of the study has been explained to me
3 personally by Dr Gibson. The side effects of interferon
4 treatment have also been explained to me."
5 Were you involved in any of the discussions about
6 treatment?
7 FATHER: No, I wasn't doing so much with him at that time
8 because, like I say, I was working away from home.
9 Q. Did your wife tell you anything about her discussions?
10 A. Whenever she came back, she was always telling me.
11 Q. What did you remember her telling you about it?
12 FATHER: I remember her telling me he was going to
13 interferon and she wasn't quite sure how he would
14 respond to it. It was supposed to be for a six-month
15 period initially but if my memory is right, I think it
16 carried on for nine months because Dr Gibson forgot to
17 notify us to stop.
18 Q. I'll take you through, actually, Dr Gibson's
19 correspondence during that period. You tell us in
20 paragraph 12 of your statement that at the time Alex
21 started interferon treatment, he wasn't displaying any
22 symptoms of the Hepatitis C virus but was -- the reason
23 given for starting the treatment was to delay the
24 progression of the virus.
25 FATHER: Yes, that's right. He never showed any sign of --

1 well, what we were explained -- of what Hepatitis C was,
2 how it would affect him. So the outward signs weren't
3 even there.

4 A. I think I did not have any jaundice or anything. I did
5 not have any of the -- you know, the outward signs --

6 Q. Do you feel you had any other signs of it?

7 A. I think I did, yes, in hindsight. I always used to get
8 bouts of tiredness. At the time I didn't -- I would
9 never have associated the two but looking back, it did
10 seem a bit strange that I would go a couple of days
11 where, you know, I would just want to stay in bed.
12 I guess for a young child I was quite tired.

13 Q. You state that you believe that Alex was the youngest
14 person to go on interferon treatment at that time.

15 FATHER: I believe that he was, and I believe he also was
16 the youngest person in Scotland to be infected with
17 Hepatitis C, when he should never have been infected
18 with Hepatitis C through blood products because it was
19 safe before he was born.

20 Q. And before Alex started the treatment, were you given an
21 idea of the likelihood of it being successful?

22 FATHER: Well, it was just given to us as a test for six
23 months to see what would happen, but there was always
24 the fear that it might not work and they would refer him
25 to something else. They weren't quite sure what effect

1 it was going to have.

2 Q. Yes. And according to that document, the consent form
3 signed, the side effects of the treatment were obviously
4 explained to either you or your wife.

5 FATHER: It was explained to my wife but when Alex was given
6 interferon, it was an awful -- I can't even go into the
7 detail of what it was like. It was horrible, absolutely
8 horrible to give it to a young child, these injections,
9 the district nurse used to come in every day and every
10 one of the family used to cringe to hear.

11 Q. Yes. You tell us in paragraph 12 of your statement,
12 which is WIT0050004, that the local nurse used to come
13 to your house three times each week and give Alex the
14 injection of interferon, and he was sick nearly every
15 time he got the injection.

16 FATHER: Yes.

17 Q. And you say at the end of that paragraph:
18 "From the start of the treatment [Alex] was tired. He
19 went into a shell and didn't want anyone to know outwith
20 the family. [Alex] being a child couldn't understand why
21 he had haemophilia and had got Hepatitis C. Even after
22 the treatment had finished, [Alex] continued to be
23 lethargic and still is."

24 FATHER: Yes.

25 Q. I would like to refer you to WIT0051007, which is

1 a letter from your GP to Dr Gibson, dated
2 31 January 1994. You say that your GP was very helpful
3 to you as a family and this is him asking Dr Gibson for
4 some further information regarding interferon treatment,
5 which she may be able to send, and he would also
6 appreciate copies of any information which is provided
7 to you in order to facilitate any discussion with you.
8 So he was obviously wanting to support you through the
9 treatment?

10 FATHER: Yes, our GP didn't know anything about interferon
11 and that's why he wrote -- he told us he was going to
12 write to Yorkhill to get information to refer back to
13 us.

14 Q. And the response he received is WIT0051008, which is
15 a letter from Dr Gibson to the GP, dated
16 3 February 1994. It's noted:

17 "As you know, [Alex] is Hepatitis C antibody-positive
18 with a moderate rise in hepatic transaminases. His
19 liver enzyme rise is in the range where interferon
20 therapy is being recommended by the Hepatitis Working
21 Party of the UK Haemophilia Directors. The Haemophilia
22 Society are running a day symposium in Glasgow this
23 month with a workshop on hepatitis. [Alex's mother]
24 contacted the Society herself and will be attending that
25 meeting. I therefore decided to see the parents

1 beforehand to try to explain some of the issues and
2 perhaps give her a fairer perspective of the problem
3 than might be represented at the meeting. If the
4 decision is taken to go ahead with the interferon
5 therapy for [Alex], then I will keep you very informed of
6 the risks and side effects. I was rather surprised that
7 [Alex's mother] did contact the society herself and felt
8 that if she had any questions, she might have spoken to
9 your haemophilia sister, but not so. I will let you
10 know the outcome of the parents' visit."

11 Do you remember --

12 FATHER: It explains it all there because of the lack of
13 information we were given in the hospital. That's why
14 we contacted the Haemophilia Society, to try and get
15 more information, because the information we got from
16 the centre, the haemophilia centre in Yorkhill, was so
17 sparse that you couldn't make head nor tail of it.

18 Q. Did you and your wife feel you got more information from
19 the Haemophilia Society to help you?

20 A. From the meeting we had, yes, a lot more than we ever
21 got in the hospital.

22 Q. Before starting treatment, Alex underwent an abdominal
23 ultrasound on 30 March 1994. The result of this is
24 WIT0051009. This notes that the liver is mildly
25 enlarged but otherwise the result is normal.

1 THE CHAIRMAN: Ms Patrick, do we know from the records when
2 the meeting with the parents took place or when the
3 Haemophilia Society meeting was?

4 MS PATRICK: Not that I have in these records.

5 THE CHAIRMAN: Let's see if you can help. Can you remember.
6 I would quite like to get the chronology as clear as
7 I can. Do you remember going to see Dr Gibson before
8 the Haemophilia Society meeting?

9 FATHER: No, it was actually my late wife that went and saw
10 Dr Gibson.

11 THE CHAIRMAN: Right.

12 FATHER: With the information that she was getting and --
13 I can't remember who the sister was at the time in
14 Yorkhill -- that's when she decided to get in touch with
15 the Haemophilia Society.

16 THE CHAIRMAN: I follow that --

17 FATHER: I can't remember what her name was.

18 THE CHAIRMAN: The letter we have seen from Dr Gibson says
19 that she wanted to see "the parents" before the
20 Haemophilia Society meeting, and I'm just trying to get
21 dates, if I can. Do you remember?

22 FATHER: I can't actually remember. I remember being at the
23 meeting but the dates, I am afraid ...

24 THE CHAIRMAN: Was it before Alex began to have interferon
25 treatment?

1 FATHER: Yes, it was.

2 THE CHAIRMAN: That at least gives us an end point, as it
3 were.

4 FATHER: It must have been between New Year and April
5 anyway.

6 THE CHAIRMAN: That's possibly as much as we can do. Early
7 1994?

8 FATHER: Yes, early 1994.

9 THE CHAIRMAN: Thanks.

10 MS PATRICK: I would like to refer to you WIT0051013,
11 which is a letter, once again, from your GP to
12 Dr Gibson, dated 16 August 1994. It states:

13 "[Alex's mother] tells me that he has been back to
14 Yorkhill several time as his interferon treatment
15 continues. The last typed letter I have from yourself
16 is dated 3 February 1994, and I wonder if it is possible
17 to have an update on Alex's treatment since then?"

18 The response to that is WIT0051014. This is dated
19 23 August 1994 from Dr Gibson to your GP. It notes:

20 "He has now been on interferon since 1 April. He
21 has tolerated this very well and we have seen him at
22 monthly intervals. There is minimal local inflammation
23 at the injection site but nil else. He has not been
24 troubled with headaches or pyrexia related to treatment.
25 He has no clinical stigmata of liver disease and no

1 hepatomegaly. His most recent LFTs show an AST of 68,
2 an ALT of 55. They therefore remain above the normal
3 range but probably have shown a little improvement."

4 Alex, how did you find taking the treatment?

5 A. I hated it. I couldn't stand it. And I did feel sick
6 from it. I just felt drained. I got -- after my first
7 treatment I was really sick. I had like extreme flu
8 symptoms and hot sweats. It was never as bad as the
9 first time but it was bad enough carrying on, and
10 I also -- because I hated going to the hospital so much,
11 I hated having to go for my appointments -- I never
12 wanted to make a big deal about it in the hospital.
13 I always tried to play down any illness I had.

14 Q. Did you miss school as a result of the interferon
15 treatment?

16 A. That combined with my haemophilia -- because I was
17 getting more joint bleeds at the time as well because
18 I wasn't on prophylaxis. I didn't want to get any more
19 injections.

20 Q. Do you feel the interferon treatment impacted on your
21 treatment for your haemophilia?

22 A. Oh, yes, definitely, massively. At the time I must have
23 just felt like a pin cushion because if it wasn't in my
24 leg it was in my arm or in my bum, and it was a long
25 time as well. I remember at the time -- I think it must

1 have been after I got home from my first treatment --
2 because it was my birthday. I think I had my first one
3 on my birthday. I had a birthday party when I came home
4 and I just remember I didn't want to be around anyone.
5 I just didn't want to have to play with anyone. I think
6 I stayed in my room. I didn't want to have to be around
7 anyone.

8 Q. Did you suffer headaches from the treatment?

9 A. I do, yes. I remember suffering them, no -- headaches,
10 not all the time but I do remember having flu symptoms
11 and just feeling generally unwell. I never wanted to
12 stress that in hospital. I always felt like if I don't
13 tell them about it, I don't have to stay, because it was
14 always such a horrible place to be.

15 Q. Could I refer you to WIT0051016. That is letter from
16 Dr Gibson to your GP, dated 17 October 1994. At this
17 time you have completed 24 weeks of interferon therapy.
18 It notes in the second paragraph:

19 "Before interferon was started, [Alex's] transaminases
20 were at least twice normal. They had normalised within
21 eight weeks of starting interferon and remained normal
22 for the following month. However, this improvement was
23 transient and his AST has been elevated at 194 and 86u/l
24 with an ALT of 251 and 110u/l during the past month. He
25 has been consistently positive for antibody to

1 Hepatitis C during the six months of interferon
2 treatment and has been PCR-positive on all but one
3 occasion. An isolated PCR negativity must attract doubt
4 on the significance. [Alex] was given interferon on
5 a trial basis. He has now completed 24 weeks of
6 interferon at 3m three times weekly, with abnormal liver
7 function tests at week 20 and week 24. This would be
8 the criteria for trial failure and withdrawal. [Alex's]
9 parents have been ardent followers of the
10 Haemophilia Society literature and meetings on
11 Hepatitis C and mother is clearly very disappointed by
12 this outcome. I have therefore agreed to continue
13 interferon for a further month while I await his most
14 recent LFTs and decide on future treatment at that
15 stage. Despite a poor response to interferon, the drug
16 has been tolerated very well."

17 So that suggests that the treatment was continued
18 for a further month after discussion with your mother?

19 A. It was always -- at that time I didn't know how long
20 I was going to be on it but I always felt it was too
21 long.

22 FATHER: I can't remember, was it a six-month time period or
23 was it a four-month time period? I can't remember. But
24 it carried on for longer and then they told us one time
25 there is no point at all. We carried on with the

1 interferon but we should have stopped it two months ago
2 but they forgot to notify us.

3 A. I think the wording in this statement --

4 FATHER: I can't remember.

5 A. -- about forgetting, I think it's more -- I don't know
6 why I have used the word "forget". I think it was more
7 my treatment was carried on when it should have stopped.
8 I never --

9 Q. Could it have been them suggesting in hindsight it might
10 have been better to stop it after the six-month period
11 rather than continuing it?

12 A. Yes.

13 Q. I will refer you to another letter, WIT0051018. This
14 is a letter from R Ahmed to Alex's GP, dated
15 16 December 1994. It notes at the start of the third
16 paragraph the latest blood test results being roughly
17 the same as the one done in October:

18 "It has been decided to continue him on interferon
19 for another month."

20 If we look at WIT0051019, this is a letter from
21 Dr Gibson to Alex's GP, dated 24 January 1995. Go down
22 to the fourth line:

23 "He has been on interferon therapy for the past
24 eight months because of Hepatitis C positivity. He
25 tolerates this treatment well although its efficacy in

1 terms of clearing the Hepatitis C virus is doubtful.
2 After six months of treatment, HCV RNA remained positive
3 but was negative when tested last month. This is the
4 first negative result we have had and in the light of
5 that we have decided to continue with interferon
6 meantime until we have the result of his most
7 recent blood test taken at this visit. If he remains
8 HCV RNA positive after nine months of interferon, it is
9 unlikely that continuing single agent treatment will be
10 effective.

11 "Combination therapy with ribavirin and interferon
12 is being reported with some success and when he next
13 attends in one month, if he remains virus-positive, it
14 may be appropriate to add ribavirin to his regime."

15 It records your most recent liver function tests,
16 AST of 180 and an ALT of 142. If we look at
17 WIT0051020, this is a letter from Dr Gibson to Alex's
18 GP, dated 20 February 1995. It notes in the second line
19 of paragraph 2:

20 "[Alex] has now been on interferon therapy for the
21 past ten months and has failed to clear the virus, as
22 measured by HCV RNA, or normalise his liver enzymes."

23 Going on to the third paragraph:

24 "Despite the fact that [Alex] has tolerated interferon
25 well, he has shown no improvement. I therefore stopped

1 treatment at this visit. A combination of interferon
2 and ribavirin is being reported to be more effective
3 than interferon alone, although the trials are small and
4 preliminary. I'm arranging for [Alex] to see our
5 hepatologist before further decisions about treatment
6 are taken. This is clearly important both in terms of
7 monitoring and treatment. [Alex] is to have a review
8 appointment in one month's time ..."

9 Which Dr Gibson hopes will be a joint visit.

10 THE CHAIRMAN: Ms Patrick, it's just short of 12. If we are
11 to give the stenographer a break ...

12 MS PATRICK: I was just going to finish off that point with
13 another question.

14 THE CHAIRMAN: That's fine.

15 MS PATRICK: I just wanted to ask you about the effect of
16 the treatment not working on you. What was your
17 reaction to that?

18 A. I think I was probably quite happy that I did not have
19 to get any more injections, firstly. I don't know.
20 I don't think it really -- it didn't really compute --
21 it didn't really mean anything. At that time I was more
22 concerned with the fact I had to get extra injections.
23 I understood that they could possibly make me better but
24 it didn't really feel very nice, you know?

25 Q. What about for your parents? What was the effect?

1 FATHER: It was very disappointing but the biggest shock was
2 how long he was on it after being told he would only be
3 on it for six months. I wasn't sure if it was six or
4 four but obviously it was six, and it carried on for
5 eight or whatever. But it was very, very disappointing,
6 very hard to deal with, because there was no improvement
7 whatsoever. He was still the same as he was before he
8 started his interferon. And the other one there, just
9 talking about what I was just saying -- sorry, I can't
10 find it now -- that they were going to put it along with
11 the interferon.

12 Q. Ribavirin?

13 FATHER: Never, ever started that.

14 A. I didn't want to --

15 FATHER: He wouldn't actually take it. He refused point
16 blank to go on any more treatment because of what he had
17 gone through getting this interferon. It was just -- it
18 doesn't bear to think about what he went through. My
19 heart still --

20 A. I think as well, because I went through it so much, that
21 my -- I never liked being in hospital because it was
22 always, like, a negative experience. It was such
23 a horrible thing that I was reluctant to say, "I have
24 had a headache," or, "I haven't been well," because
25 I would have to stay longer, and then the same thing

1 happens, you stay, there is tension, you have to go
2 back. The way I felt at the time was I go back every
3 three months anyway so -- or at that time I was there
4 every month. So it was just kind of -- it was
5 interfering with my regular life.

6 THE CHAIRMAN: I think we are getting the impression that
7 before you started on interferon treatment, so far as
8 you were concerned, there really were no consequences
9 for you of liver problems. You then went through this
10 extremely unpleasant treatment, with no indication of
11 any improvement in your position at all. Is that the
12 sort of background to your being unwilling really to --

13 A. It was also a time of discovery as well because,
14 although I knew I had Hepatitis C, I didn't know what
15 that meant. I knew it was bad and I shouldn't have it
16 and I needed to get rid of it but I guess I was
17 overhearing conversations that my parents had had, maybe
18 that they didn't want me to hear, and I was putting
19 things together and I was starting -- maybe not
20 necessarily at this time, maybe a year later or two
21 years later I would start thinking, "Have I got a time
22 limit? If I don't do this or" --

23 THE CHAIRMAN: That probably does come a bit later on in the
24 history and not at this precise time.

25 A. I think I must have had some -- I must have been coming

1 to these kind of conclusions, thinking about, you know,
2 that this had a negative effect on my health at this
3 time. It's just a long period of discovery.

4 FATHER: I am afraid his parents had the same feelings.

5 THE CHAIRMAN: Indeed. I think I can understand that.

6 Okay, we will have a short break now and then come back.

7 (12.05 pm)

8 (Short break)

9 (12.18 pm)

10 THE CHAIRMAN: Yes, Ms Patrick.

11 MS PATRICK: Thank you.

12 After the treatment with interferon was stopped
13 in February 1995, Alex, you continued to attend
14 Yorkhill Hospital for monitoring. The records show that
15 in June 1995 you had an episode of raised bilirubin,
16 WIT0051029 but this resolved itself.

17 In 1996 Dr Gibson obtained advice about further
18 treatment for you, and the reference for this is
19 WIT0051040. This is a letter from TJ Evans,
20 consultant paediatrician, to Dr Gibson, dated
21 21 February 1996. In the first paragraph:

22 "Further to your letter regarding [Alex] and whether
23 he should have a repeat course of interferon ..."

24 It records the treatment you had already received
25 and then, in paragraph 3:

1 "The literature suggests that a higher dose, 5 or 6
2 million units three times a day, may be more efficacious
3 but this is not clearly established in children.

4 I do not know of any evidence of changing from one
5 manufacturer's product to another being likely to be
6 advantageous. I do not have a note of the genotype of
7 the Hepatitis C infecting [Alex] and clearly this would
8 have a bearing on the likelihood of response; being much
9 less if he is 1B."

10 There is a genotype test result showing that you are
11 1A, WIT0051059, but we don't need to look at that.

12 It's dated August 1998. It also notes:

13 " ... if we had some indication of the number of
14 copies of RNA per ml present in [Alex's] serum, we would
15 have some indication of whether he is more or less
16 likely to respond ...

17 "In summary there is not a clear answer to whether
18 treatment at a higher dose should be used. It is
19 a balance of discomfort, inconvenience and an increased
20 risk of side effects against the hope of clearing the
21 virus."

22 It's suggested that your genotype of the virus is
23 determined and quantification of the viral RNA and then
24 put the pros and cons to your parents.

25 If we could look at WIT0051041, this is a letter

1 from Dr Chalmers to Alex's GP, dated 15 May 1996,
2 following a review clinic appointment on 3 May 1996. If
3 we go over the page to 1042, it's noted:

4 "As far as his Hepatitis C is concerned, he had
5 a repeat hepatic ultrasound carried out prior to clinic,
6 which was normal. His liver function tests remain
7 mildly abnormal with an AST of 82 and ALT of 138. The
8 question of whether [Alex] should receive a further trial
9 of interferon at a higher dose has been raised.
10 However, it's difficult to know whether he is likely to
11 respond to 6 million units three times a week, having
12 failed on a regime of 3 million units three times
13 per week."

14 It's noted that they are arranging to determine your
15 genotype of the virus and your viral load and that you
16 will be reviewed again in the clinic in three months'
17 time.

18 If we could turn, please, to WIT0051048, this is
19 a letter from Dr Chalmers to Alex's GP, dated
20 31 January 1997, recording that you had been seen again
21 at the clinic on 24 January 1997 for review. If we
22 could go over the page, please, to 1049, in the last
23 paragraph it records the results of your liver function
24 tests and notes that they have therefore remained fairly
25 stable recently:

1 "He last had an ultrasound scan carried out in May
2 of last year and we will book a repeat scan for his next
3 visit in April. [Alex's mother] obviously still has
4 a number of unanswered questions regarding [Alex's]
5 hepatitis and she has arranged to spend some time
6 discussing these after her next visit. I have, however,
7 indicated to her that I think it is unlikely that Alex
8 will be eligible for the combined interferon/ribavirin
9 trial which is about to start, as this seems principally
10 designed for patients who became Hepatitis C virus
11 negative while on interferon but subsequently relapsed
12 following its withdrawal. [Alex] would not fall into this
13 category as he neither showed evidence of clearing the
14 virus or of improvement in his liver function tests
15 while on treatment. He will be seen again for review in
16 three months' time."

17 So it appears that your mother was keen to continue
18 to pursue options that may be open to you for treatment
19 of the virus?

20 A. Yes.

21 Q. Is that --

22 A. I think so. I was never keen on it, keen on keeping
23 up -- staying on treatment or trying new treatment, more
24 for the fact I didn't want to get more injections.

25 THE CHAIRMAN: I think the first page of the letter suggests

1 you were still sort of resisting prophylactic treatment
2 for your haemophilia also at this stage.

3 A. I was, yes.

4 THE CHAIRMAN: Fairly consistent?

5 A. Yes, I probably started my teenage years a little early.
6 It was always such a horrible experience having to go to
7 hospital because there was always -- like I said a few
8 times in the past -- tension. It was never a pleasant
9 experience. I definitely resisted it.

10 MS PATRICK: Annually you received ultrasound scans, which
11 continued to be normal up until May 2000, and your liver
12 function tests remained raised but not enough to cause
13 concern. Obviously, during this period you started
14 secondary school, and how did you find that?

15 A. I found it pretty hard. I found it quite hard to make
16 friends. I never really had any best friends because
17 I always felt like I had a tonne of secrets and baggage
18 that I had to carry around with. It was hard enough to
19 tell people that I had haemophilia let alone anything
20 else. I felt quite withdrawn because of that, because
21 I knew I had something to hide and I never really felt
22 like I could open up or explain why I was going away
23 every other month or what I was doing. I still do to
24 this day. I am still quite closed.

25 Q. Were you still in a wheelchair in secondary school?

1 A. Not so much in secondary school because it was a bigger
2 school and it would have been harder for me to get
3 around. So I tended -- my bleeds changed as well. I
4 could go to school when I had a bleed. I probably
5 shouldn't have but I chose not to use a wheelchair when
6 I had a bleed. I would rest it and then carry on going.

7 Q. Did you continue to miss quite a lot of school due to
8 bleeds?

9 A. I did, yes.

10 Q. How did that impact on your school work?

11 A. Well, it definitely wasn't a positive. I was going
12 through -- my target joints were developing a lot more
13 then, so I had persistent bleeding into my right knee
14 and my left ankle. I wasn't very keen -- I didn't like
15 being the disabled boy at school. I felt like I was
16 labelled with that anyway because I was the only one
17 with that condition.

18 THE CHAIRMAN: Did the school know?

19 A. They knew about my haemophilia. I don't know if they
20 knew about my Hepatitis C.

21 FATHER: No, the school didn't know about the Hepatitis C.

22 THE CHAIRMAN: So far as the haemophilia was concerned, did
23 the school have special arrangements for you?

24 FATHER: Yes. Well, at that time there was no mobile
25 phones. They hadn't come into being. But we had

1 a pager and the school had the numbers, so if anything
2 happened to him in school, they would just ring the
3 pager. If they didn't get an answer at home on the
4 phone, they would ring the pager and then myself or my
5 late wife would head for the school to see what was
6 wrong --

7 THE CHAIRMAN: That would be your response: you knew there
8 was a problem so the first thing is to get some of the
9 concentrate and take it to the school or what?

10 FATHER: We had it at home. So he was on home treatment.

11 THE CHAIRMAN: Did you take Alex home then?

12 FATHER: Oh, yes, it's only five minutes.

13 THE CHAIRMAN: Sometimes we forget how close things can be.

14 FATHER: It was just a case of either going home to get the
15 factor or taking him home. It was probably easier to
16 take him home anyway.

17 THE CHAIRMAN: Thank you.

18 MS PATRICK: I notice reference in your medical records to
19 you having been made to wear a helmet in gym.

20 A. Yes.

21 Q. And the hospital wrote on your behalf that you felt
22 stigmatised by that and the hospital wrote a letter to
23 your teachers explaining that that wasn't strictly
24 necessary.

25 A. It is worth pointing out that in the first and second

1 year I was in the same school as my primary school. So
2 I didn't change up until the big school, until third and
3 fourth year, so many of the problems I had in the first
4 and second year were similar to the problems in primary,
5 it was just more of a case of -- there was new kids
6 coming to the school. So making relationships with the
7 new kids was a bit strange, in regards to the last
8 question.

9 Q. As you got older, did you start to think more about the
10 Hepatitis C virus and what it might mean for you?

11 A. Yes, I guess I started on more of a personal quest for
12 information because I didn't feel -- I didn't really
13 know anything about it. I knew in my head I should find
14 out but I was kind of scared what I was going to find
15 out. I had little handout booklets from the hospital
16 but I just -- it was just hard for me to take in the
17 information at that age.

18 Q. Did you tell any of your friends about it?

19 A. Not really. I told one -- I told my best friend at the
20 time about it. In primary school I probably mentioned
21 it to everybody. I didn't think it was a big deal.
22 I didn't attach the stigma to it.

23 Q. It was an illness.

24 A. Yes. So I probably did in passing say to some of my
25 mates, I was just getting my Hepatitis C jab, but

1 I didn't realise until later on that actually it's not
2 really the kind of thing you want to tell everybody at
3 school.

4 Sorry, just back to your question about the head
5 gear, I did have head gear in the first and second year
6 and I didn't like that either. It was like a rugby
7 scrum cap I was made to wear for a couple of weeks until
8 I eventually didn't wear it.

9 Q. There is a record in the medical records of the hospital
10 writing to say that that wasn't necessary. Could
11 I refer you to WIT0051069? This is a letter from
12 Dr Chalmers, dated 23 November 2000, asking Dr Morris
13 for his opinion on the management of your treatment. It
14 notes that:

15 "At the present time he remains clinically well and
16 his LFTs are essentially normal. He has never had
17 a liver biopsy. I would be grateful on your opinion as
18 to whether we should continue any further treatment for
19 him at the present time."

20 Could I refer you next to WIT0051070? This is the
21 response from Dr Morris to Dr Chalmers, dated
22 21 February 2001. It notes that at that time you are
23 14 years old and in your third year at school and
24 studying your standard grades. How did you get on with
25 your standard grades?

1 A. I probably could have done better with my standard
2 grades. I did quite well in one or two subjects I was
3 passionate about.

4 Q. What were they?

5 A. [REDACTED]

6 [REDACTED]

7 Q. How many standard grades did you pass?

8 A. I think six. I passed them all. Actually no, I failed
9 physics, I did fail physics, but I passed all of them.

10 Q. It states:

11 "Although he has Hepatitis C, this does not seem to
12 have any impact upon him and he denies excessive fatigue
13 or primary liver symptoms. He still manages to play
14 football and basketball without any problems... he has
15 never had a liver biopsy but approximately five years
16 ago he received interferon monotherapy, which
17 unfortunately was unsuccessful."

18 It records that you have two brothers and one
19 sister, all of whom are well. The next paragraph, which
20 is taken out there, is:

21 "Examination revealed a well looking young man in
22 whom abdominal examination was normal. In the clinic
23 today I discussed with [Alex] and his mother the possible
24 benefits of combination therapy. I have mentioned that
25 it is our policy to consider liver biopsy in patients

1 whom we are retreating with combination therapy. [Alex]
2 is happy with the information that we have given him and
3 we have agreed that they will consider the pros and cons
4 of further combination therapy and the potential risks
5 of liver biopsy before returning to this clinic in three
6 months. In the meantime we have rechecked a number of
7 pre-assessment drugs that will be required if he were
8 to go on combination therapy."

9 You then underwent a further ultrasound of your
10 abdomen in August 2001 and the result of this is
11 WIT0051072 and is essentially normal. It's at the
12 bottom of this page. Could I refer you next to
13 WIT0051073? This is a letter from Dr Morris to your
14 GP, dated 15 August 2001. It notes that:

15 "[Alex] remains essentially asymptomatic and I have
16 not suggested that we change his management. I did ask
17 him whether he had considered the possibility of further
18 treatments or indeed liver biopsy, but he did not seem
19 to have done. The main impression I have at the moment
20 is that he does not wish to progress his assessment of
21 treatment at the present time but may wish to do so in
22 a few years, once he has passed his adolescence. I am
23 going to see him on a yearly basis in the clinic."

24 What was your view about having a liver biopsy at
25 the time? Do you remember?

1 A. At that time I didn't want one. I didn't see the point.
2 I didn't feel like I had any main symptoms from it. To
3 be honest, I just kind of ignored it. I didn't think
4 about it too much. I didn't feel like I was sick at
5 that point. So there wasn't anything to treat almost.
6 I was also -- I was quite worried about having a liver
7 biopsy as well, obviously being a haemophiliac, and also
8 I kind of heard that the combination of ribavirin and
9 interferon, the side effects can be quite extreme. So
10 I didn't really -- I just didn't really consider it.

11 Q. So Dr Morris's impression there was right in that you
12 weren't keen to consider treatment at that time?

13 A. At that point, yes.

14 Q. You attended again the following year in September 2002.
15 I'll give you the reference for this document but there
16 is no need to look at it. It's WIT0051076. It's
17 noted there were no primary liver symptoms:

18 "His liver screen was negative and abdominal
19 ultrasound normal last year... we both felt that no
20 specific intervention was required for Hepatitis C at
21 the present time..."

22 In paragraph 15 of your statement, at 0038, you tell
23 us that you left school at 16 years of age and you went
24 to study arts and social sciences at your local college.
25 Where was your local college?

1 A. In [REDACTED].

2 Q. Where in [REDACTED] was it?

3 A. [REDACTED]. In the main town.

4 Q. How long was that course?

5 A. [REDACTED]

6 [REDACTED]

7 [REDACTED]

8 [REDACTED]

9 [REDACTED]

10 Q. Right.

11 THE CHAIRMAN: Where did you go in Glasgow?

12 A. I went to [REDACTED]

13 MS PATRICK: So you spent less than a year at the college in

14 [REDACTED] and then you moved down to Glasgow?

15 A. Yes.

16 Q. And that was to do a [REDACTED] course. Which college was

17 that at?

18 A. [REDACTED]

19 THE CHAIRMAN: Is it still an independent one or is it one

20 of the ones that have all been amalgamated?

21 A. I'm not sure.

22 THE CHAIRMAN: You do not know.

23 MS PATRICK: How long did you attend that course in Glasgow

24 for?

25 A. I completed the first year. I passed the first year.

1 I found it quite hard, being away from home. I think
2 I was probably -- I was maybe a bit young to move away.

3 Q. And you continued to attend Dr Morris's clinic for
4 monitoring. Can I refer you to WIT0051078. This is
5 a letter from Dr Morris to your GP, dated
6 20 January 2004, noting that really there has been no
7 change in your condition and that you have declined to
8 consider treatment at this stage. Could I refer you
9 next to WIT0051086? Essentially the same picture,
10 that you are quite happy with things at present:

11 "... and I have therefore simply arranged to check
12 his bloods."

13 This is a letter by J Gray to your GP, dated
14 11 January 2005. At this point are you still at the
15 [REDACTED] course in Glasgow?

16 A. 2005? Yes, I think I would have been, yes. I always
17 found -- when I moved away from home, I was quite -- for
18 my hospital appointments, I was quite happy just to go
19 in and -- just go in and get them done and leave really.
20 Also, I didn't find I had any problems relating to my
21 Hepatitis C at that point. I wasn't really interested
22 in treatment or exploring anything any further. I did
23 look into treatment myself a little bit but I didn't
24 want to pursue it.

25 Q. No. Did you think you had symptoms of fatigue at that

1 time?

2 A. I think so, yes. I think I had them all through that
3 time. It was more like from out of nowhere I found it
4 would happen. I would just suddenly get really, really
5 tired and even at that point, I guess I didn't really
6 put it together. I didn't really associate it with
7 Hepatitis C.

8 Q. Can I refer you next to WIT0051091? This is a letter
9 from Dr Morris to your GP, dated 15 June 2006, following
10 a review at the liver clinic on 12 June 2006. It's
11 noted that you are:

12 "... asymptomatic from a liver viewpoint and... [your]
13 recent liver function tests were satisfactory and also
14 abdominal ultrasound was reassuring."

15 At that time you had troublesome symptoms of acid
16 regurgitation. Did you get treatment for that?

17 A. Yes, it did help. I'm still on the same treatment.

18 Q. Could I refer you next to WIT0051092?

19 This is a letter from Dr Alvi, an associate
20 specialist in the haemophilia and thrombosis centre at
21 Glasgow Royal infirmary to Dr Morris, dated
22 10 April 2007. It's asking if you could be seen ahead
23 of your next appointed clinic time with a view to
24 discussion of possible biopsy and treatment. It notes:

25 "He is obviously concerned about progression of the

1 condition and keen to seek your opinion. He is still
2 having bleeding episodes although his... reflux appears to
3 have settled to quite a degree."

4 This seems to be a change of heart on your part.
5 What caused that?

6 A. I think it was a combination of a lot of things. I was
7 finding it quite hard living in Glasgow and getting
8 around the city, just even my joints and things were
9 starting to seize up. My knee was getting especially
10 bad and I think I -- over a short period of time I just
11 started to care a bit more that I had Hepatitis C and
12 I started to almost think about it and research it. And
13 I guess over a period of time it just hit me that it is
14 actually really serious.

15 From a young age -- I can't remember if I found it
16 on the Internet or where I found it but I found
17 something that said patients with Hepatitis C can expect
18 to live for 20 years. So I think that was -- took time
19 to settle in my head. So I guess at that point I was
20 getting close to 20. So I suppose somewhere in my head
21 I must have thought my time was getting kind of close.

22 Q. And the response to that letter is WIT0051093 from
23 Dr Morris to Dr Alvi, dated 3 May 2007. Dr Morris
24 regrets he is about to leave for a sabbatical and so
25 it's difficult for him to give you an appointment before

1 his return. And he is sorry not to be able to offer an
2 earlier solution to your request.

3 A. This was around about the time my mum was sick as well.
4 So I think that, combined -- that took a lot of things
5 to the forefront of my mind and I guess I grew up quite
6 a lot when that happened, and I guess I thought it was
7 time to start taking things a bit more seriously.

8 Q. Yes. So you attended a clinic appointment with
9 Dr Morris in October 2007. The reference for this is
10 WIT0051096. In fact, I think you were seen at that
11 time by Dr Watson because the letter is from him to your
12 GP, dated 31 October 2007. It says that you attended
13 the clinic with -- I am afraid it has been deleted out.
14 Who --

15 A. My girlfriend at the time.

16 Q. It's noted you are feeling well:

17 "... and has developed no new symptoms. We had a
18 discussion today regarding his Hepatitis C, previous
19 attempted treatment (monotherapy) and possible treatment
20 strategies. [Alex] was initially seen here
21 in August 2001. At that time he was not keen on
22 treatment for his Hepatitis C as monotherapy had been
23 attempted in 1994 for nine months with no biological
24 response. Since then he has been doing fairly well,
25 although in the last couple of years he has moved house

1 several times and has not actually been seen at the
2 clinic for one or two years."

3 It notes that you have never had a liver biopsy or
4 the genotype assessed, although I think we have seen
5 that it had been assessed in 1998:

6 "I discussed this gentleman with Dr Morris, who
7 suggested that he could have a liver biopsy under
8 ultrasound guidance, plus a Hepatitis C genotype. Alex
9 is planning on moving between ..."

10 Can you help us fill in the blanks there?

11 A. It would have been [REDACTED]. Well, actually,
12 when my mum got sick, I moved back home but I had been
13 thinking about moving to [REDACTED] at that point.

14 Q. Right. So basically it was looking a bit uncertain as
15 to where you were going to be staying at that point? Is
16 that fair to say?

17 A. Yes. I was -- I have got this -- in section 16 of my
18 statement it's relating to this meeting I had, because
19 I remember quite well, because I wanted to see Dr Morris
20 and ask him some questions and it was a junior doctor
21 that was there and I was asking her the questions and
22 I remember she would go out of the room to speak to
23 Dr Morris -- he was in the next room -- and we could
24 hear, through the air conditioning, the conversation and
25 it didn't feel very nice listening to him talk about me

1 just in the next room without coming in to explain it.
2 I felt like it was a really big thing that I was
3 considering and yet he wouldn't even come in to talk
4 about it.

5 Q. Going back to this letter, it's noted that you chose to
6 continue your care for your Hepatitis C there for the
7 time being:

8 "As such, we are arranging an ultrasound-guided
9 biopsy of his liver. For this he will need to be
10 admitted beforehand to correct his clotting and then
11 afterwards for observation."

12 The plan is to do that in November and you had your
13 blood taken for various tests. The results of the blood
14 tests are specified in a letter dated 15 November 2007.
15 The reference is WIT0051097. It's a letter from
16 C Kong to your GP. We can see there that, compared to
17 your previous liver function test, your transaminase is
18 slightly up.

19 PROFESSOR JAMES: For the record, "raised albumin" is good;
20 it means your liver is working really well.

21 MS PATRICK: Thank you.

22 I think the records show that, although it was
23 planned to have an ultrasound-guided biopsy of the
24 liver, that didn't happen.

25 A. Yes.

1 Q. Why was that?

2 A. I went to the hospital on the day I was supposed to get
3 it done and I had the cannula in my hand and it was only
4 at that point -- I think the liver nurse came up to have
5 a -- to speak to me, just briefly, just to make sure
6 I wanted to go ahead with it, and she asked me if I knew
7 what my genotype was and I said I didn't know and she
8 explained that that would have a massive impact on the
9 treatment and the success rate, and she went to find
10 that out. She told me I was genotype 1 and there was
11 a much lower chance of clearing the virus than if it was
12 a different genotype, and also Dr Alvi, my consultant,
13 came from upstairs to double-check and I think I just
14 got quite scared that two of these people were asking me
15 if I felt okay and if I wanted to continue on.

16 At that point I said, "Maybe I need to think about
17 this. Maybe I need to think whether I'm doing the right
18 thing."

19 Q. So you were concerned about the risks of the liver
20 biopsy?

21 A. Yes. I wasn't up until -- I mean, I was concerned about
22 them but I wasn't fully concerned. I don't think
23 I really understood it until Dr Alvi came up and said,
24 you know, "This is quite serious for a haemophiliac to
25 be getting this."

1 Q. So you changed your mind and left without having the
2 liver biopsy carried out?

3 A. Yes.

4 Q. You tell us, at the end of paragraph 16 of your
5 statement, which is at page ending 0038, that you moved
6 to [REDACTED] in [REDACTED]. Why did you decide to move
7 to [REDACTED]?

8 THE CHAIRMAN: Sorry, before we go on to [REDACTED], I think
9 I would like to fill in just a little bit. I think we
10 know now that when you went to discuss what for you was
11 really a major change in attitude, that, might move
12 towards biopsy, you were disappointed that Dr Morris
13 didn't see you.

14 A. Yes, I felt quite let down.

15 THE CHAIRMAN: On this date you find yourself in the
16 hospital and a fairly material change taking place in
17 the advice you had. In between those two events had you
18 seen someone who explained to you about biopsy or what?

19 A. No, I had researched it myself on the Internet. You
20 know, I must have found tonnes of information but
21 I didn't necessarily know what was right and what was
22 incorrect. But I had made a mental decision that maybe
23 now is the time to do so something about it and if
24 I have to get a biopsy to get the treatment, maybe it's
25 worth it.

1 THE CHAIRMAN: How did you get the appointment? Did it come
2 through the post -- for the biopsy?

3 A. I'm not sure. I attended -- at that time I attended the
4 Royal Infirmary quite frequently to pick up my
5 treatment, so I would have assumed, if it didn't come by
6 post, I may have picked it up at the --

7 THE CHAIRMAN: Do you remember any discussion about it,
8 about the implications of biopsy for you as
9 a haemophilia patient, at about that time or were you
10 dependent just on your own researches?

11 A. I definitely didn't speak to Dr Alvi about it until that
12 day. I assume I would have spoken to Dr Morris but
13 I think -- well, maybe I didn't speak to Dr Morris.
14 I think it was one of his assistants.

15 THE CHAIRMAN: Dr Watson?

16 A. Yes.

17 THE CHAIRMAN: The young lady doctor?

18 A. Yes. But it wasn't until Dr Alvi -- I got worried the
19 fact that he had come upstairs just to see me, to make
20 sure I was -- you know, to make sure I was doing the
21 right thing.

22 THE CHAIRMAN: I think I can understand that. If I were
23 sitting with a cannula in and someone came along and
24 said, "Do you really want to do this," I think I might
25 have had the same reaction as you did.

1 But that was what brought Dr Alvi down, to give you
2 the advice that caused you really to pause at that
3 stage?

4 A. Yes, he just wanted to make sure I fully understood the
5 implications of getting a biopsy as a haemophiliac.

6 THE CHAIRMAN: Yes. Thank you very much.

7 A. I had considered them but not maybe considered them
8 fully.

9 THE CHAIRMAN: Yes, there is nothing like being confronted
10 by a fairly senior consultant and asked to think about
11 it, to make you apply your mind to it, is there?

12 A. I saw it as just a hurdle I would have to go through to
13 maybe get treatment that might help.

14 THE CHAIRMAN: Yes, thank you.

15 MS PATRICK: Thank you. I had referred you to paragraph 16
16 of your statement, when you told us that you moved to
17 ██████ in February 2008 and I had asked you why you
18 moved from Glasgow to ██████.

19 A. There was two things. My girlfriend at the time was
20 down here and somebody had also said that the ██████████
21 was a good hospital. I knew somebody that was attending
22 it.

23 Q. Had you finished your ██████ course at college in
24 Glasgow?

25 A. I had finished it, yes, unsuccessfully. My attendance

1 was a bit poor and I just didn't -- I just didn't get to
2 finish it.

3 Q. So how many years did you manage to attend the college
4 for?

5 A. Two years in total, I think, almost two years.

6 Q. And why do you feel that your attendance was poor?

7 A. I think it was to do with my haemophilia. I also --
8 I found it hard because I was going through all this,
9 like, discovery with my Hepatitis C as well. I guess my
10 mind was quite preoccupied. I also -- I found it hard
11 to get close to people, so I was quite withdrawn in
12 a lot of this, so I didn't -- I guess that's what
13 contributed.

14 Q. Yes. Since you have moved to [REDACTED], your treatment in
15 respect of the Hepatitis C virus is being provided by
16 the [REDACTED]. Do you attend, is
17 it, a joint hepatology and haemophilia clinic there?

18 A. Yes, it is a joint clinic. I do attend different
19 appointments for each one. Because I get Fibroscans.
20 I find that the care is quite good care. I feel like
21 I get offered quite a lot.

22 Q. How often do you go to clinic appointments there?

23 A. Every three months -- every six months, I think.

24 PROFESSOR JAMES: Do you see Professor Dusheiko or ...?

25 A. It's Dr [REDACTED].

1 PROFESSOR JAMES: Oh, right.

2 MS PATRICK: Have you had a liver biopsy carried out there?

3 A. I haven't had a liver biopsy, no. I have slightly
4 considered it but I feel that now that I get
5 a Fibroscan, it's better than the ultrasound, so ...

6 PROFESSOR JAMES: Do you know the result of the Fibroscan,
7 the most recent one that you have had?

8 A. Yes, I think the last one was 6.8.

9 MS PATRICK: I think I might be referring you to a letter
10 that has got the results in.

11 PROFESSOR JAMES: Sorry.

12 MS PATRICK: Don't worry, it might not be the most recent
13 result.

14 I was going to ask you to look at WIT0051103,
15 please. This is a letter from Dr [REDACTED] to your GP, dated
16 20 October 2009. In the first paragraph -- it has been
17 taken out of there but it is recorded that you are
18 [REDACTED]
19 [REDACTED].

20 A. Yes.

21 Q. When did you start that?

22 A. I started that in 2009, I think it was. Sorry, was it
23 2008 or 2009? 2008, I think it was.

24 Q. So when you moved to [REDACTED], is that what you did?

25 A. That wasn't my initial plan, but I really felt like

1 I wanted to continue the studies that I had been doing
2 in Glasgow and I felt that that was the best -- I just
3 felt like I needed to do that.

4 THE CHAIRMAN: [REDACTED]

5 [REDACTED]?

6 A. [REDACTED]

7 THE CHAIRMAN: [REDACTED]

8 A. [REDACTED]

9 [REDACTED]

10 [REDACTED]

11 THE CHAIRMAN: [REDACTED]

12 [REDACTED]

[REDACTED]

13 [REDACTED]

14 [REDACTED]

15 A. [REDACTED]

16 [REDACTED]

17 [REDACTED]

18 [REDACTED]

19 [REDACTED]

20 MS PATRICK: The blood test results taken at that time are
21 recorded in the second paragraph. Could I refer you
22 next to WIT0051106? This is a letter from Dr Yee to
23 your GP, dated 21 March 2011. So this is the most
24 recent letter that was in your medical records.

25 It's noted -- well, I can see it -- that you have

1 graduated as a [REDACTED] by this time?

2 A. [REDACTED]

3 [REDACTED]

4 [REDACTED]

5 [REDACTED]

6 [REDACTED]

7 FATHER: Can I point out one mistake there? His

8 first treatment wasn't in Glasgow, it was in Inverness.

9 Q. Yes.

10 FATHER: Sorry.

11 THE CHAIRMAN: I wouldn't worry too much about that. We

12 have got the full record. We won't be misled by that.

13 MS PATRICK: Yes.

14 I was going to refer you to the Fibroscan results in

15 2010, which showed a reading of 6.8, and you are

16 continuing on prophylaxis therapy.

17 You mentioned in paragraph 16 of your statement that

18 you have been told by a doctor, or maybe doctors, in the

19 [REDACTED] hospital that you should consider treatment

20 for the Hepatitis C virus while you are healthy enough

21 to withstand the side effects of it and so this has left

22 you confused as to what the best course of action for

23 you to take is.

24 What is the position now in relation to treatment?

25 A. Like I said, they are quite good at the [REDACTED] to

1 offer me whatever treatment there is available. At the
2 moment -- I did get quite close, probably about a year
3 ago, to trying interferon -- I think it was the new
4 interferon/ribavirin treatment -- but my doctor at the
5 time said there is actually probably a better treatment
6 coming out in 12 to 18 months, so I might as well hold
7 off until that comes round.

8 Q. You tell us in paragraph 19 of your statement, which is
9 0039, that you have suffered symptoms of the Hepatitis C
10 virus throughout your life and sometimes did not realise
11 the full extent of them:

12 "I have often been depressed, angry, tired and
13 lethargic and sometimes haven't put this down to the
14 illness as it is very difficult to recognise these
15 symptoms within [you]."

16 Have you ever received treatment for depression?

17 A. No, I have never -- I have never really -- I don't
18 really talk to many people about it. It took me a while
19 to think that I might even be depressed. I think having
20 the condition so long, so many, like, underlying
21 psychological things. Until I met my girlfriend,
22 I guess I did not even consider them until she said, you
23 know, "In some of your thoughts you are not quite
24 right," just in terms of, like, my outlook on life and
25 certain things I do -- not certain things I do but just

1 my overall outlook.

2 FATHER: When he started this -- after he started this
3 interferon treatment, he was -- we didn't realise it was
4 depression at the time. He was just going away all
5 on his own, wouldn't come out. He would spend days and
6 he would hardly eat and we just thought, well, it's just
7 the effect of the interferon that's causing it, but
8 obviously it wasn't. It was just an ongoing thing right
9 up until he moved away from home, what he was like. Now
10 I don't see him so often but -- I had a very hard time
11 when his mother died.

12 A. I always found it hard as well to talk to my mum and dad
13 and anyone else because all my experiences of going to
14 the hospital were very negative, so everything
15 surrounding having haemophilia and Hepatitis C was all
16 really negative. I tried to speak to my mum about it on
17 occasion but it wasn't a very nice thing to do.
18 I always found it, you know, really hard.

19 THE CHAIRMAN: Would you have a look at the time?

20 MS PATRICK: Yes.

21 You say at the end of that paragraph that your
22 family, especially your mother, cared for you
23 extensively while you were growing up and you rely a lot
24 on your girlfriend now, when you suffer. Have you ever
25 expressed the feelings of depression to a doctor?

1 A. Not really. When I was in Glasgow, I did mention it to
2 one of my GPs. I can't remember the name of the GP -- I
3 will have a note somewhere. I said I was just finding
4 it hard at college at the time, just being away from
5 home. I think I had been away from home for two years
6 at that point. I was starting to discover a lot of
7 things about Hepatitis C and I guess I did not really
8 know what depression was. I did not understand that,
9 let alone anything else. In hindsight it's quite easy
10 to look back and say actually I was pretty miserable and
11 down about it.

12 Q. In paragraph 17 of your statement you tell us that the
13 prognosis for your medical condition is unknown and
14 differs from person to person and, statistically, as you
15 have had the virus for over 20 years, you have a one in
16 five chance of chronic liver disease and scarring of the
17 liver, which can lead to cancer and other terminal
18 illnesses. Does that remain your understanding of the
19 prognosis?

20 A. Yes, kind of. I mean, I do research it and look into
21 it. It has probably slightly changed since then -- that
22 was a few years ago. But I do try and understand it
23 a bit more.

24 Q. Yes.

25 A. But also, because I was never really offered any advice

1 at the hospital -- limited advice, I never really fully
2 understood it.

3 THE CHAIRMAN: One of the problems might be that it is very
4 difficult to understand it. I'm trying to understand
5 quite a lot of it myself.

6 We will have a break now.

7 (1.08 pm)

8 (The short adjournment)

9 (2.00 pm)

10 THE CHAIRMAN: Yes?

11 MS PATRICK: I would like to refer you to paragraph 18 of
12 your witness statement as we turn to look at the
13 impacts of your infection with Hepatitis C on you and
14 your family. You tell us in paragraph 18 that it has
15 been devastating on your life and having grown up [REDACTED]
16 [REDACTED], as we have heard, your
17 family were naturally very apprehensive about telling
18 people about your infection.

19 Because of this, you say you grew up feeling very
20 embarrassed about your situation and it was very
21 difficult to discuss your condition openly with your
22 family, as you always felt different and removed.

23 You say:

24 "I could not discuss my condition with friends and,
25 as such, I always felt removed from other children. In

1 terms of my own family, it is so complicated to even
2 consider having children that I just don't bother. The
3 risk of passing on an infection and then the thought of
4 not being around to see my children grow up really
5 prevents me from planning any kind of family life."

6 Does this remain your view about the future?

7 A. Yes, I mean -- it's pretty much the same. I don't
8 really think about having kids -- I would love to get
9 older and have children but it's not really something
10 I can begin to consider at the moment.

11 Q. Have you discussed the prospect of that with your
12 doctors?

13 A. Not in any detail. I have briefly touched on it with
14 Dr [REDACTED], my doctor at the [REDACTED].

15 Q. Yes, and what have you been told about the risk of
16 passing the infection on?

17 A. Just that there is a risk. I think she might have said
18 there is a possibility of, like, IVF and stuff to lower
19 the risk of infection to my partner. Not that I'm
20 anywhere near considering it at the moment.

21 Q. I wonder if either you or your father are able to say --
22 it's difficult to express, I know -- what the effect of
23 your infection with Hepatitis C was on your mother.

24 A. It was huge, obviously, especially me being the
25 youngest, and I'm sure my dad will agree, having two

1 other brothers and an older sister, caring for them and
2 looking after them and then right at the end I came
3 along and I have got all these problems and baggage
4 and -- I guess for you guys, it must have been a lot to
5 go through.

6 FATHER: It was quite a lot.

7 A. That has an impact as well because I know that and
8 I have to kind of -- I feel -- I guess I feel like
9 I carry that.

10 Q. What about you? What has been the effect of the
11 infection with Hepatitis C on you?

12 FATHER: It has had a big effect on me and the whole family
13 as a whole we're, as a family, very close, and it has
14 just been heart breaking to have one out of five of us,
15 you know, with this condition. Why? This is the
16 question I have always had. Why?

17 Q. Do you think it affected your brothers and sister?

18 FATHER: Sorry. They are very much aware of it but it's
19 not -- like we said before, it's not a thing we discuss
20 unless he gets ill with an illness and then we speak
21 about it. If he is not well and we find out he is not
22 well [REDACTED], we discuss and try and find out is
23 it affected with hepatitis.

24 A. I do feel really close with my family in many ways but
25 it's quite hard to explain. In many ways it's

1 a strained relationship. We are close but I'm quite
2 closed and I think as a family we generally don't talk
3 about it. It's always there, obviously, but it's hard
4 to talk about.

5 Q. Yes.

6 FATHER: It's just a difficult subject to broach within the
7 family because we feel -- I don't know how to explain --

8 A. I think it's also because that's how we have coped with
9 it. We have coped with it by -- when I was young we
10 just got on with it. We went to the appointments and we
11 had all the discussions and then we went back home,
12 discussed about some more and then we just didn't talk
13 about it. It was there and you could talk about it but
14 we just chose not to, and in many ways I guess it has
15 been a good thing and a bad thing, probably more
16 detrimental than anything, but it's just how we got on
17 with it.

18 Q. And you touched on that in relation to your social life
19 as well and your group of friends, that you were quite
20 closed, and in paragraph 27 you say that you find it
21 difficult to make close friends and associates, as you
22 never want to get too close to people because you then
23 feel you have to tell them about your condition. You
24 say you don't have a massive circle of friends and don't
25 really get involved in any kind of community life.

1 A. Even coming down here today, I have had to take two days
2 off work and, you know, you do not want to have to say,
3 "By the way, I have got haemophilia -- oh, and I also
4 have got Hepatitis C and I need to go to this Inquiry".
5 It's this whole big thing that you have to explain.
6 It's not like you can tell every person you meet and
7 have a quick explanation of, "Oh, that's a shame. It's
8 terrible that that could have happened." You have this
9 whole other big baggage of information that you have to
10 carry and explain. I almost feel like I have to defend
11 it if I do tell anybody, which is why I generally choose
12 not to.

13 Q. So do your work know that --

14 A. No.

15 Q. You are here today? No?

16 A. They know I'm here today but I didn't explain fully.

17 I just said I'm spending time with my dad.

18 THE CHAIRMAN: They know you're in [REDACTED] but they don't
19 know what you are doing here.

20 A. Yes, I have explained to them I'm going up to see my dad
21 but I haven't told them I'm here.

22 MS PATRICK: In paragraph 21 you tell us about the impact of
23 the Hepatitis C virus and perhaps your haemophilia
24 impacts on it a bit too, that you are still continuing
25 [REDACTED], are you?

1 A. Not really as much any more. I was having a lot of
2 problems with my knee and I had an arthroscopy to repair
3 damage, so I have been kind of not really doing as much.
4 I had an arthroscopy in 2008 -- sorry, 2009. And it
5 helped a lot with the haemophilia problems.

6 Q. You say you are generally confined to nonphysical
7 activities. You enjoy watching films, listening to
8 music and attending concerts. But you can't play impact
9 sports of any kind and find it difficult to do
10 activities that keep you fit but don't exhaust you.
11 Would you say that's a combination of the Hepatitis C
12 virus and your haemophilia?

13 A. I would say so, yes. Since I have had my operation,
14 I've been trying really hard to build up strength in my
15 legs and muscles, because that's part of the problem,
16 I just don't have a lot of muscle mass in my legs. I do
17 find it hard to sustain physical activity. I try very
18 hard at the moment because I'm trying to keep healthy.

19 Q. At the end of that paragraph you state that you worry in
20 case you get injured and have to deal with telling
21 people of your infection. Is that in case you have an
22 injury producing blood?

23 A. Yes, just like a cut or something, you know. You always
24 worry about it.

25 THE CHAIRMAN: Does your present job as [REDACTED] have any

1 physical element to it at all?

2 A. Not really. It's quite relaxed in terms of I can take
3 breaks when I want, I can work from home. I'm
4 part-time. I can do a lot of my work on the Internet.
5 So there is not really any physical activity, which
6 suits me quite well.

7 MS PATRICK: You speak about work in paragraph 20 of your
8 statement, the page before, and state that you always
9 found it difficult to sustain any level of work. You
10 have worked in bars, coffee shops and attended college
11 but have always found it difficult to sustain, mainly
12 due to the immense bouts of fatigue that you suffer.
13 They are completely unpredictable and not constant:

14 "so I can sometimes just be completely unreliable in
15 the workplace, which doesn't make me the best kind of
16 employee. At college I found it difficult to
17 concentrate and motivation has always been hard because
18 I never feel like I can truly plan for the future. My
19 dream in life was always to be a pilot but due to my
20 condition ..."

21

22 A.

23

24 Q.

And:

25

"I also loved [REDACTED] but again, I could never

1 consider this as a professional occupation [because]
2 I just get too exhausted. I feel like a bit of
3 a failure on the work front and it is always difficult
4 when I compare myself with friends my age who seem to be
5 progressing with their lives."

6 You said there that you are working part-time at the
7 moment. What are your hours?

8 A. It's pretty relaxed. I would say I work -- I kind of go
9 in around about 12 and then I'll finish around four.
10 It's just to, like, learn what the company do and ...

11 Q. Are you enjoying the work?

12 A. Yes, I am. The best thing about it is it's quite
13 relaxed. There is always work to be done but it's
14 a case of you do it or you come back to it, and the
15 people I work with are quite accommodating with my
16 haemophilia, because I have told them about that.
17 I told them about that straight away.

18 Q. [REDACTED]

19 A. [REDACTED]

20 [REDACTED]

21 Q. [REDACTED]

22 [REDACTED]

23 [REDACTED]

24 [REDACTED]

25 [REDACTED]

1 A. [REDACTED]
2 [REDACTED]
3 [REDACTED] I still qualify for DLA but I have a car
4 to help me get round. I don't actually get the money.
5 But I have always found that -- nobody else in my family
6 has ever been on benefits or any -- you know, any kind
7 of handouts and that's always a bit of a crutch in my
8 mind as well, because my dad has never done it, my
9 brothers and uncles and aunties. It has always been
10 something I have felt quite guilty about. I have never
11 enjoyed it or been proud of it.

12 Q. You note there that you accumulated massive debts,
13 including an overdraft and credit card bills, and
14 I think the extent of these is about £18,000. Is that
15 right?

16 A. It's probably a bit less than that because I'm
17 managing -- I'm attempting to pay them off. When I was
18 in college and studying, I just -- I never took out
19 a student loan or anything and I just was always
20 reckless with money. I never really thought I was going
21 to have to live long enough to have to pay them off --
22 rather stupidly I suppose, but I think I'm better with
23 my finances now.

24 Q. Do you feel you are going to manage to pay this off in
25 the future?

1 A. Eventually, yes.

2 Q. Yes. I mean, at the time of that statement, you were
3 saying you got called by debt collectors almost every
4 day and your financial situation impacted massively on
5 your state of mind. It caused you massive amounts of
6 anxiety, and you say:
7 "[It] can lead to me becoming depressed."
8 Do you still have these feelings in relation to your
9 debt?

10 A. I do still worry about it, yes. I have consolidated
11 a lot of them but I pay them off a minimum amount
12 a month. So I don't have people calling on me or
13 anything. I feel like I'm in control of them a bit more
14 but obviously they are still there.

15 Q. You tell us in paragraph 25 that you received £20,000
16 from the Skipton Fund in 2004 and you paid off some
17 debts, gave some money to your family and spent the rest
18 on rent while you were at college in Glasgow and on
19 equipment which you needed for your course. And that
20 money lasted two years.

21 A. Probably just more than two years. We went on a family
22 holiday as well, to Canada, to visit some relatives.
23 Yes, I was just stupid with that money. I feel bad
24 about that now but at the time I was just immature and
25 I didn't really think I would need it for later life.

1 I didn't expect to have a later life. As naive as that
2 was at that age, I was just reckless.

3 Q. And you tell us in paragraph 23 that you do not qualify
4 for any mortgages because of your condition:

5 "This leaves me unable to ever consider buying my
6 own house. I have not actually applied for a mortgage
7 but I have researched the possibility."

8 Is that due to your Hepatitis C virus?

9 A. Yes, I think so.

10 Q. And do you have any life assurance?

11 A. No.

12 Q. Have you ever applied for it?

13 A. No.

14 Q. In paragraph 26 you tell us that you find it difficult
15 to travel abroad because of the expense of travel
16 insurance and obviously your financial situation
17 generally. [REDACTED]

18 [REDACTED]
19 if you could do anything, it would be to travel more:

20 "but I can't see it happening any time soon. Living
21 in [REDACTED], most of my [REDACTED]
22 [REDACTED]."

23 It's noted in a questionnaire that the Inquiry
24 received a copy of, that when you went to America, you
25 had to pay £150 more than, was it one of your relatives,

1 for a ten-day holiday to America?

2 FATHER: It would have been for when we went to Canada. We
3 paid £100 for his travel insurance but myself and my
4 wife's was only 32 between us. So it was just
5 ridiculous. I think it's in his statement or my
6 statement.

7 Q. Yes, it's paragraph 17. You say that you were £32 and
8 the travel insurance premium for Alex was over £100 due
9 to the fact he had haemophilia and Hepatitis C.

10 FATHER: It was actually £109. Since I made the statement
11 I looked it up and it's 109.

12 Q. You have obviously had to travel a lot to appointments
13 and I take it the family has incurred the travel expense
14 of getting to and from these appointments?

15 A. No, we claimed back some -- when I was young, we claimed
16 back the -- the flights were paid by the health board
17 because obviously there was no haemophilia unit in
18 [REDACTED]. So it was always the health board that paid for
19 the flights there and back. There would be extra costs
20 incurred if the rest of the family went but we always
21 stayed with my auntie in Glasgow.

22 FATHER: If there was any time that he had to stay in bed
23 and breakfast or a hotel, whatever, for overnight, you
24 couldn't claim the full expense -- I can't remember the
25 percentage -- because I was in full-time employment and

1 you didn't qualify for income support. I think it's
2 income support. You couldn't get the full payment back.
3 So every time we went to Glasgow, it was costing us
4 money.

5 THE CHAIRMAN: Did you get help for Alex, a share of it?

6 FATHER: No.

7 THE CHAIRMAN: None at all?

8 FATHER: No, the health board paid for the flight and
9 a percentage of the overnight expenses. There was no
10 meals, nothing else.

11 THE CHAIRMAN: Yes. I find it quite difficult to see how
12 a percentage worked. Did they have a fixed amount that
13 they gave you or was it an actual percentage of your
14 outgoings?

15 FATHER: You were allowed, I think, £28 per night. I think
16 that's what it was.

17 THE CHAIRMAN: I think it would be that.

18 FATHER: You couldn't get bed and breakfast for £28 a night.
19 When you look back at these statements, we were down
20 there every month and it was quite a big chunk of any
21 savings that we had.

22 THE CHAIRMAN: Yes. I think that's quite important, really,
23 that you were stuck with the -- whatever the fixed
24 allocation for the time being was, even though that
25 wasn't a sufficient amount to meet the cost to you.

1 It's another aspect of living in a remote area, you see.

2 FATHER: Yes, it has got its pros and it has got its cons.

3 A. It was always quite difficult as well because if we did
4 stay in Glasgow, we would stay with my auntie.

5 THE CHAIRMAN: And they were not sympathetic to that.

6 A. It was just the fact that you had to go to the hospital
7 and go back and explain what was going on and answer
8 questions, and just stuff like that was always a bit
9 difficult.

10 MS PATRICK: Have you incurred any other expenses as
11 a result of the Hepatitis C virus?

12 A. Just things like travelling, just like in [REDACTED],
13 [REDACTED].

14 Q. Getting to your clinic appointments?

15 A. Fortunately I have got a [REDACTED] Pass now, so travel
16 costs aren't too bad.

17 Q. What about heating costs? Do you feel you have had to
18 heat your home more?

19 A. Yes, heating costs as well. I didn't really consider
20 that. I guess that would come into it as well.

21 Q. Do you feel cold?

22 A. Yes, I feel like I have got bad circulation ironically,
23 in my toes and fingers. It's always hard to know
24 what -- the things I'm feeling, if it's a cause of
25 Hepatitis C or not, I always find. Because I have

1 always had it. There is not like one point where
2 everything changed and I started feeling unwell. It has
3 always been there. It's quite difficult.
4 Q. Have you ever had to pay anybody to help you in the
5 house or elsewhere due to the virus?
6 A. Not really. I wouldn't ever -- I wouldn't want to have
7 to do that. I would rather -- I'm more likely to
8 struggle on my own than ask for ...
9 Q. Thank you very much.
10 THE CHAIRMAN: Do you have any questions, Mr Di Rollo?
11 MR DI ROLLO: No, thank you, sir.
12 THE CHAIRMAN: Mr Anderson?
13 MR ANDERSON: No, thank you, sir.
14 MR JOHNSTON: No, thank you, sir.
15 THE CHAIRMAN: Thank you very much.

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(The Inquiry adjourned until 9.30 am the following day)

I N D E X

ALEX	1
Questions by MS PATRICK	1

