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Tuesday, 7 June 2011

(9.30 am)

THE CHAIRMAN: Ladies and gentlemen, as you know, I would normally administer the oath at this stage but there is a problem, of course, in respect that an anonymous witness cannot effectively take the oath and I'm proposing to dispense with that stage, if that's acceptable to parties.

CHRISTINE

Good morning. Thank you very much for coming. The bit of business I have just dealt with is purely formal and does not affect your evidence in any way whatsoever. So we will just begin and see how we get on.

A. Okay.

THE CHAIRMAN: Yes, Ms Patrick.

Questions by MS PATRICK

MS PATRICK: Good morning, Christine. You are being referred to, for the purposes of today's hearing, as Christine. Although that's not your real name. I thought it would be helpful for you if I explain a bit about who is here today. Lord Penrose has introduced himself and sitting next to him is Oliver James, the medical adviser to the Inquiry. In front of him we have Maria McCann, who is the secretary to the Inquiry and Oliver, who is helping with the documents.

1 We have two stenographers who are recording
2 everything that's said this morning and they will
3 produce the transcript at the end of today's hearing and
4 that is the transcript that you will be able to look at
5 and see if you wish any further information to be
6 redacted from it.

7 I think you have met us. Sitting behind us is
8 Yasmin Shepherd, who is one of the paralegals for the
9 Inquiry, and in the front row here we have the lawyers
10 representing the various parties who are involved in
11 this Inquiry and we have two advocates, who are
12 representing the patients, relatives and Haemophilia
13 Society. We have an advocate and a solicitor on behalf
14 of the health boards in the middle. Then we have an
15 advocate and solicitor sitting behind him, who is
16 representing the government.

17 I think you know the man on the front row, here to
18 give you moral support.

19 Now, you helpfully, some time ago, provided the
20 Inquiry with a statement and you should have a hard copy
21 of that in front of you. I think Margaret is going to
22 get you a copy. All these documents have numbers which
23 I'm going to ask to be shown on the screen. So the
24 witness statement is WIT0040027. Can you see that on
25 the screen?

1 A. Yes, I can.

2 Q. That's the witness statement that you provided to the
3 Inquiry with the redactions that we agreed between us --

4 A. Yes.

5 Q. -- that have been made to it. Are you happy for me to
6 carry on without a hard copy just now?

7 A. Yes, that's fine.

8 Q. You will see in paragraph 1 you say that you are
9 54 years old. Is that out of date?

10 A. Yes, very much so. I'm nearly 56 now.

11 Q. Right, okay. And you are married and we redacted your
12 employment from there but would you like to tell us
13 about your employment?

14 A. I'm a [REDACTED]. To [REDACTED]
15 [REDACTED].

16 Q. How long have you done that for?

17 A. I have been doing that now for eight years.

18 Q. Did you work before that?

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

20 Q. And how long were you a [REDACTED]?

21 A. 20 plus years. As a [REDACTED], yes.

22 Q. So you are very experienced in [REDACTED]?

23 A. Yes.

24 Q. I think you and your husband used to run your own
25 business?

1 A. Yes, we did, we had our own [REDACTED].

2 Q. Was that in the local area where you lived?

3 A. Yes, that was in the village that we lived in at that

4 time.

5 Q. Okay, thank you. As you say at the start of paragraph 1

6 of your statement, your statement is twofold and covers

7 your own personal story and that of your deceased son,

8 [REDACTED].

9 A. Yes.

10 Q. And [REDACTED] became infected with HIV from blood

11 products?

12 A. Yes, that's right.

13 Q. And you yourself acquired Hepatitis C from blood

14 products?

15 A. Yes.

16 Q. You will be aware that in this block of hearings, the

17 Inquiry is focusing on the effects of infection with

18 HIV?

19 A. Yes.

20 Q. So much of the focus of your evidence today will be in

21 respect of [REDACTED]'s story. That is not to minimise

22 what has happened to you --

23 A. No, I understand.

24 Q. -- in respect of your infection with Hepatitis C.

25 Moving on to paragraph 2 of your statement, you tell

1 us there that [REDACTED], being your eldest son, had
2 Haemophilia A and he contracted both HIV and Hepatitis C
3 following receipt of infected Factor VIII. You say that
4 he was diagnosed with haemophilia aged about six weeks?
5 A. Yes.
6 Q. Was there any indication before then?
7 A. [REDACTED] was born breach and he was bruised from the
8 neck down, so he was in childcare -- you know, he was in
9 an incubator for the first six days. But the reason we
10 found out that it was haemophilia was we had a wee
11 rocking chair for him, a metal frame-chair, and his
12 cheek became swollen and when I phoned the doctor, he
13 then referred us to the hospital thinking that we had
14 abused him and that's how we knew he was a haemophiliac
15 so early.
16 Q. So when he was born and he was bruised, what did the
17 doctors say about that at the time?
18 A. They never said anything. They didn't say anything
19 about it at the time. I reminded them there was
20 haemophilia in the family but they didn't seem to do
21 anything about it at that point.
22 Q. Right. So haemophilia wasn't mentioned to you by the
23 doctors when he was born?
24 A. Not at first.
25 Q. No. You said there that there was haemophilia in the

1 family?

2 A. Yes.

3 Q. Would you explain that, please?

4 A. I had two brothers with haemophilia. I have got
5 a cousin that's a haemophiliac. My uncle was
6 a haemophiliac as well.

7 Q. We discover later on in the statement that you are
8 a carrier of haemophilia yourself?

9 A. Yes.

10 Q. Were you aware when [REDACTED] was born that you were
11 a haemophilia carrier?

12 A. No, I did not.

13 THE CHAIRMAN: Can I ask a question? You say the doctors
14 didn't mention haemophilia when [REDACTED] was born?

15 A. No.

16 THE CHAIRMAN: At that stage were you in touch just with the
17 obstetric department and your GP or were you meeting
18 other doctors?

19 A. No, it was just my GP.

20 THE CHAIRMAN: Just your GP?

21 A. Yes.

22 MS PATRICK: Could I refer you to a document which is
23 a letter from Dr Willoughby. It's WIT0040062. It
24 should come up on the screen in front of you.

25 As you will see, this is a letter from, if we scroll

1 down a bit, Dr Willoughby, consultant haematologist,
2 dated 4 July 1975. This is a letter to Dr Forbes at
3 Glasgow Royal Infirmary and it's basically notifying him
4 that your son has haemophilia?

5 A. Yes.

6 Q. As you will see, it states:

7 "I would like to notify you of the following
8 patient, aged four months, in whom we have recently made
9 a diagnosis of haemophilia."

10 He then mentioned obviously, your family history and
11 says that you have been investigated and found to be
12 a carrier. When were you investigated?

13 A. I don't remember ever being investigated.

14 Q. Do you remember being investigated when [REDACTED] was
15 born?

16 A. No.

17 Q. The letter reads:

18 "He developed spontaneous bruising of his right
19 cheek at the age of four months."

20 Which I think must be the incident you were talking
21 about. We found an AHG assay of less than 1 per cent
22 and the Factor IX assay was 70 per cent. Then the final
23 paragraph asks that he be registered as under the
24 clinical care of Dr Shanks's unit at the Royal Hospital
25 for Sick Children and:

1 "Could you also send the parents the haemophilia
2 card plus the usual literature."
3 What was the haemophilia card?
4 A. It's just a medical card that tells you that he is
5 haemophilia, just a wee green card.
6 Q. What did you use it for?
7 A. He was supposed to have it with him at all times so that
8 if anything happened -- he became unconscious -- that
9 they had a kind of medical idea as to what was wrong
10 with him.
11 Q. Yes. "Usual literature", did you get sent some
12 information?
13 A. They send you information about the Haemophilia Society
14 and that's about it. If you want to investigate that
15 further, you can.
16 Q. So they direct you towards the Haemophilia Society as
17 a way of providing information?
18 A. Yes.
19 Q. Were you given any information directly from the
20 hospital, that was made up by the hospital?
21 A. No, not really.
22 Q. No, okay.
23 A. I think the fact that I have got family that are
24 haemophilia, they possibly assumed that I knew more than
25 somebody that was new to it.

1 Q. Yes. How affected were your brothers with haemophilia?

2 A. They are both serious -- one of my brothers is now dead

3 but my older brother, he is less than 1 per cent as

4 well.

5 Q. The brother who is dead, was he less than 1 per cent?

6 A. Yes.

7 Q. So you were brought up with brothers with haemophilia.

8 So you knew what it involved?

9 A. Yes.

10 Q. Could we go back to your statement, to WIT0040027,

11 paragraph 2. You tell us towards the bottom of

12 paragraph 2:

13 "Throughout [REDACTED]'s short life, he was cared

14 for at the Paediatric Haemophilia Unit at the Royal

15 Hospital for Sick Children."

16 Which I think was known as "Yorkhill" --

17 A. Yes.

18 Q. -- in Glasgow and then latterly he became an adult

19 patient at Glasgow Royal Infirmary?

20 A. Yes.

21 Q. Who was in charge of his care at Yorkhill?

22 A. The doctor?

23 Q. Yes, the doctor.

24 A. It was Anna Pettigrew. We tended to see more than...

25 Q. Dr Willoughby was obviously mentioned in the letter --

1 A. Yes, he was the centre director.

2 Q. He was the centre director, right. Then you tell us
3 that his care was managed by Professor Lowe and
4 Sister Ishbel McDougal. Was that at the
5 Glasgow Royal Infirmary?

6 A. That's right.

7 Q. And then later on in his life he was treated at
8 Ruchill Hospital under the care of Professor Kennedy and
9 that was in relation to his symptoms of HIV?

10 A. Yes.

11 Q. You tell us, if we move on to page 2, that for a short
12 spell you moved -- I think it was to England, you moved.
13 Is that right?

14 A. Yes, it was.

15 Q. In 1980 for a few months. Did [REDACTED] have
16 treatment in England while you were there?

17 A. Yes, he did. We had to go to the hospital in Newcastle
18 because he had had a fall and all they gave him for the
19 first couple of days was bed rest. They wanted to know
20 how long we were staying because they weren't going to
21 order in any Factor VIII if we weren't going to be there
22 full-time and that was the reason we ended up coming
23 home. But by the time we did come home, he had to have
24 his leg back slabbed because he had been immobile for so
25 long. So he had to have intensive physiotherapy when we

1 came home.

2 Q. So he had had a bleed in his leg and you had gone into
3 hospital and all they did was bed rest for two days.

4 A. They bed rested him for a couple of days and then they
5 gave him Factor VIII.

6 Q. But you felt that there had been a long delay in --

7 A. Yes.

8 Q. How long was he in hospital when you got the
9 Factor VIII?

10 A. I think he was only there about four or five days and
11 then we came home.

12 Q. Right. I get the impression from this -- and please
13 correct me if I am wrong -- that you felt that the care
14 was better in Yorkhill?

15 A. Yes.

16 Q. The care that you got in Newcastle?

17 A. Yes.

18 Q. Okay. Moving on to paragraph 3, you tell us about
19 ██████████'s treatment for his haemophilia and tell us
20 that from 1975 to 1980 he was treated with
21 cryoprecipitate. Was this to treat bleeds as and when
22 they occurred?

23 A. Yes.

24 Q. Yes. And actually you say there that when he was
25 a toddler he had more frequent bleeds?

1 A. Yes.

2 Q. How often did he have a bleed as a toddler?

3 A. It felt like all the time because we never molly coddled
4 him. We treated him like a normal child and within
5 reason let him do what he wanted to do, and obviously
6 that led at times to him having bleeds.

7 Q. Right.

8 A. I can't say how often.

9 Q. Every week?

10 A. It felt like it.

11 Q. When he had a bleed what did you do?

12 A. If it was at the weekend we had to go through Accident &
13 Emergency and wait for a doctor to come down and see him
14 and diagnose that he had a bleed.

15 Q. And that was presumably even though you knew he had
16 a bleed?

17 A. Yes.

18 Q. He had been treated in hospital before for bleeds?

19 A. Yes.

20 Q. But there was no way to get directly to the haemophilia
21 unit at that stage?

22 A. The way it eventually was was that if it was between
23 Monday and Friday, we could phone the wards -- it was
24 Ward 7A that there was a haemophilia clinic up there --
25 and tell them that we were coming up. So we could

1 bypass Accident & Emergency but it was weekends that
2 were a nightmare.

3 Q. Because presumably when you went to Accident &
4 Emergency, they had to call for a haematologist to come
5 down?

6 A. Yes.

7 Q. Would there be a delay in that?

8 A. There was always a delay.

9 Q. And the bleeds continuing to happen and then
10 a haematologist would arrive and confirm that he needed
11 treatment with cryoprecipitate?

12 A. Yes.

13 Q. Would he then be admitted to the ward?

14 A. He would be put on to a bed and given the
15 cryoprecipitate and then if they felt he was okay, we
16 would take him home and then bring him back had he had
17 to come back again.

18 Q. Right. How long did a treatment with cryoprecipitate
19 usually last?

20 A. It could take up to an hour. It all depended how much
21 they diagnosed him to have, how severe the bleed was.

22 Q. Were there occasions when you felt able to just look
23 after [REDACTED] at home rather than take him to the
24 hospital?

25 A. When he was in home treatment, that was the only time.

1 Q. That was later?

2 A. Yes.

3 Q. But if he had a bleed as a toddler would you assess it
4 yourselves if you felt that bed rest was enough?

5 A. I would never have done that. If he had a bleed we
6 always took him to the hospital.

7 Q. Did he always need cryoprecipitate when you got there?

8 A. Yes.

9 Q. Were there times he needed to stay in hospital longer
10 than an hour or two for the cryoprecipitate?

11 A. Not very often.

12 Q. No. So you would usually get home within the same day?

13 A. Yes.

14 Q. Going back to the difficulties of going through Accident
15 & Emergency and how weekends were worse than during the
16 week, was there a time, when during the week, you also
17 had to go through A&E?

18 A. Before they got the unit set up in Ward 7A, it always
19 had to be done through Accident & Emergency. I can't
20 remember how long that lasted for, though.

21 THE CHAIRMAN: I'm sorry for interrupting but there is
22 someone here with a telephone switched on. Whoever it
23 is, get it off, please. I don't want the remotest risk
24 of anyone communicating outside of this room. It is
25 down as a Burness visitor, I notice, that I see

1 frequently when I'm warned that there is a transmission
2 from this room. Get it off and make no use of it at
3 all. Thank you.

4 If it is yours, don't take the row seriously.

5 MS PATRICK: I think some of the lawyers are guilty too.

6 Moving on, I think you have touched on the fact that
7 you tried to let [REDACTED] live as normal a life as
8 possible. I think we all know that boys generally have
9 a tendency to be more active sometimes than girls. How
10 was it for you bringing up a boy with haemophilia?

11 A. I have lived with it all my life. So you have got let
12 him have his life. He wasn't a foolish boy. He
13 occasionally took chances but not very often. You know,
14 he always used to err on the side of caution and draw
15 the reins in if he saw his friends doing silly things.
16 But his friend were sensible too and they knew he was
17 a haemophiliac, and I think they responded to that with
18 him.

19 Q. How did he find it going to hospital at a young age for
20 his treatment with cryoprecipitate?

21 A. He had never known any different. It was just something
22 that happened to him that he just had to deal with.

23 Q. If we move on to paragraph 4, which is the next page,
24 ending 0029, you tell us about the change in
25 [REDACTED]'s treatment, Factor VIII.

1 A. Yes.

2 Q. This was in about 1980, when [REDACTED] was about five
3 years old?

4 A. Yes.

5 Q. He was first given this in hospital?

6 A. Yes.

7 Q. And you say:

8 "We thought it was wonderful stuff."
9 Why did you think that?

10 A. Because it was able to be mixed so quickly and it was --
11 I mean, it was injected there and then instead of having
12 to wait until the cryoprecipitate dissolved and
13 everything was right with that -- and he didn't have to
14 sit for hours.

15 Q. Right. And what were you told by the doctors or nurses
16 about Factor VIII at the time his treatment with it
17 started?

18 A. I'm sorry, I don't understand what you mean.

19 Q. Did they explain to you what Factor VIII was and how it
20 was made?

21 A. No, not really.

22 Q. No?

23 A. No.

24 Q. So were you told it was a new treatment?

25 A. Yes, we were told it was a new treatment to replace

1 cryoprecipitate and it would help the bleeds disperse
2 much quicker, cause less joint troubles.

3 Q. So it wasn't explained to you how the Factor VIII was
4 made?

5 A. No.

6 Q. Were you ever warned of any risks associated with
7 Factor VIII?

8 A. My husband did ask about risks and they said that, you
9 know, there were risks with everything that was taken.
10 It was just kind of brushed under the carpet when
11 he asked about it.

12 Q. Were you given any other information about the safety of
13 Factor VIII?

14 A. No.

15 Q. Had you been warned of risks of cryoprecipitate?

16 A. No.

17 Q. No. This might be hard for you to answer but you say
18 your husband was told there were risks with everything?

19 A. Yes.

20 Q. What did you take from that?

21 A. That -- it's hard to answer. I can't ...

22 THE CHAIRMAN: If you want a break at any stage.

23 MS PATRICK: Are you all right?

24 A. I'm fine.

25 Q. Can you remember if there was any mention of a risk at

1 all of hepatitis or liver disease from Factor VIII --

2 A. No.

3 Q. -- treatment?

4 A. No, I was never warned about that.

5 Q. So you weren't warned about that?

6 A. No. After [REDACTED] died -- we didn't even know he

7 had Hepatitis C, and after [REDACTED] died I asked one

8 of the nursing staff if [REDACTED] did have it and she

9 said, "Oh, yes, all of our boys have got it". Just

10 a matter of fact, off the cuff remark.

11 Q. We are going to come on to that.

12 A. Oh, right sorry.

13 Q. I think if we could turn to paragraph 12 of your

14 statement, which is at WIT0040032, you say there,

15 about the third line down:

16 "The doctors were perceived by us to be gods. We

17 trusted them and didn't question the treatment they were

18 giving [REDACTED]. We accepted that they were giving

19 him the best treatment available because that was what

20 they told us."

21 A. Yes.

22 Q. Did they tell you that?

23 A. Yes.

24 Q. That it was the best treatment?

25 A. Yes, it was the best treatment available.

1 Q. You then go on to say that:
2 "No one warned us about the risks."
3 That you had no reason to think that the blood
4 products that your son was getting would not be clean:
5 "We had no idea that blood was being collected from
6 paid donors in America because in Britain we were used
7 to blood being collected from unpaid volunteers."
8 You then mention that you heard from your brother
9 that some of the haemophilia patients in Oxford were
10 refusing to be treated with American Factor VIII
11 manufactured by Armour.
12 A. Yes.
13 Q. "but the doctors at Yorkhill reassured us that it was
14 safe and there was no chance of cross infection."
15 A. Yes.
16 Q. So can you remember when that was? I appreciate it's
17 a very long time ago.
18 A. No, I can't remember.
19 Q. But did you ask the doctors at Yorkhill about it?
20 A. Yes, we did.
21 Q. And they reassured you?
22 A. Yes.
23 Q. At the time that [REDACTED] first was given
24 Factor VIII, did you know that there was a difference in
25 some of the products, in that some were manufactured by

1 the Scottish National Blood Transfusion Service?

2 A. Yes.

3 Q. And that some were brought in from America?

4 A. Yes.

5 Q. Was that explained to you?

6 A. The way it was explained to us was that the American

7 Factor VIII was much better.

8 Q. How was that?

9 A. Because it dissolved easier. We sometimes had a problem

10 trying to get the Factor VIII to dissolve with the

11 sterile water but they said that it was dissolved easier

12 and it seemed to react better in stopping the bleed from

13 getting any worse.

14 Q. Right. From the beginning of his Factor VIII treatment,

15 did [REDACTED] get a mixture of these?

16 A. Yes.

17 Q. The only difference you thought was that the commercial

18 American Factor VIII was better -- easier to make up?

19 A. Yes.

20 Q. Was that right?

21 A. Yes.

22 Q. If we turn to a document, which is in fact a treatment

23 sheet. The reference is WIT0040063. This is headed

24 up "Royal Hospital for Sick Children, Glasgow

25 Haemophilia Centre". It's a treatment sheet in respect

1 of [REDACTED]. As you will see, it dates from
2 27 June 1980 through to the end of 1980, where there is
3 a line scored along and then it goes on through 1981 and
4 over the page as far up as August 1982.

5 Could we go back to the first page? You will see
6 that from June 1980 [REDACTED] received 12 treatments,
7 being a mixture of cryoprecipitate and Factor VIII.
8 Then if you scroll down, there is a spate of cryo
9 in March and April and then more Factor VIII. So this
10 gives us a rough idea, I think, of the treatments which
11 [REDACTED] needed in that time spell --

12 A. Yes.

13 Q. -- and how many there were?

14 A. Yes.

15 Q. Having counted them up, there were 43 treatments in
16 1981, some of which did involve home training, which we
17 can see mentioned, I think. The first mention is
18 in July 1981. I think if we go back to paragraph 5 of
19 your statement, which is WIT0040029, you tell us in
20 paragraph 5 about when you were trained to administer
21 home treatment of Factor VIII to [REDACTED] yourself.

22 A. Yes.

23 Q. You were trained alongside other parents to administer
24 home treatment on a prophylactic regime rather than
25 a reactionary regime to actual bleeds?

1 A. That's right.

2 Q. Up until then was [REDACTED] only receiving treatment
3 in response to his bleeds?

4 A. Yes.

5 Q. When you were trained after that, you started giving him
6 prophylactic treatment at home?

7 A. Yes, we used to do it twice a week.

8 Q. Right. You tell us a bit about what your training
9 involved. How did you find the training?

10 A. It was fine.

11 Q. It was fine?

12 A. Yes.

13 Q. Your husband allowed you to inject him with sterile
14 water as practice?

15 A. Yes.

16 Q. Were you warned of any risk of prophylactic treatment in
17 comparison to just treatment in response to bleeds?

18 A. No, if we had been warned we wouldn't have done
19 prophylactic treatment.

20 Q. How did the prophylactic treatment help [REDACTED]?

21 A. It did to a degree. On the odd occasion he had to have
22 Factor VIII because he had sustained an injury.

23 Q. Right.

24 A. But it did help, giving him it prophylactically.

25 Q. So you could give him treatment twice a week and if he

1 had a bleed and it felt like he needed more treatment,
2 would you administer that yourself?

3 A. Yes, I had a diary where I recorded everything, all the
4 Factor VIII that we used and the reason it was used and
5 all the batch numbers on it.

6 Q. I was going to look at the system that was in place for
7 you giving [REDACTED] home treatment. You used to
8 collect the Factor VIII from Yorkhill?

9 A. Yes.

10 Q. How often was that?

11 A. As often as we needed it. So it could be on a weekly
12 basis or it could be two weeks. It just all depended.

13 Q. How much would you be given?

14 A. I think it was two boxes we used to get at a time, it's
15 hard to remember.

16 Q. And how long -- how many --

17 A. I think there was 10 in a box.

18 Q. Right. How many would you use for each treatment?

19 A. I think I gave him two.

20 Q. Right. So a box could last you, if it is twice
21 a week -- yes, two and a half weeks maybe.

22 A. Mm-hm.

23 Q. Okay. Then you would take the boxes home, use them and
24 keep a note. You say you kept a diary?

25 A. Yes, Yorkhill gave us a diary for it, similar to the

1 one -- exactly the same as the one you just showed
2 a second ago. And we would put on it the reason for it,
3 the batch numbers and any reaction.

4 Q. Okay. What happened to the record that you kept?

5 A. When it was filled, when the book was filled, we gave it
6 back to Yorkhill and they would give us another one.

7 Q. Right. And you say that you then would carry on taking
8 him to the clinic for blood tests?

9 A. Yes, just to make sure that everything was okay.

10 Q. Okay. Did there come a time when [REDACTED] was able
11 to treat himself?

12 A. Yes.

13 Q. Yes. Did he use to help you get his factor ready before
14 he was trained himself?

15 A. On the odd occasion, but he is a boy. As little as he
16 could do, he would do.

17 Q. We have a document, I think, which shows that by the age
18 of 14, I think, [REDACTED] was giving himself factor.
19 It's WIT0040080. Is that his handwriting there?

20 A. Yes, it is.

21 Q. We can see that in the column "injected by", it is
22 "self". He has kept a record of the date and time, the
23 reason for the bleed, the site of the bleed and the
24 number of bottles used and also comments, which I think
25 you touched on there: if there were any adverse

1 reaction.

2 A. Yes.

3 Q. Thank you. Could we return to your statement and move
4 on to paragraph 7, which is at 0030. This is moving on
5 to how you acquired the Hepatitis C virus, which I think
6 was around this time --

7 A. Yes.

8 Q. -- when you had just been trained in home treatment of
9 [REDACTED]. You have said in the statement that it was
10 in 1975 you discovered that you were a carrier of
11 Haemophilia A. Do you think it was around then?

12 A. It possibly was, I don't remember them doing any tests
13 on me but to produce a haemophiliac, it can only be
14 assumed that I'm a carrier.

15 Q. Maybe [REDACTED]'s birth triggered some investigation
16 in respect of that. You then tell us that, given your
17 genetic predisposition, you made the considerably
18 difficult decision to have a sterilisation performed?

19 A. Yes.

20 Q. It was carried out at [REDACTED] Hospital in [REDACTED]
21 in December 1981 and prior to surgery Dr Willoughby, who
22 we have heard was in charge of the haemophilia care at
23 Yorkhill, checked your Factor VIII levels and discovered
24 that you only had 26 per cent Factor VIII. But up until
25 then you hadn't thought of yourself as a haemophilia

1 patient?

2 A. No, not at all.

3 Q. And you hadn't had any treatment --

4 A. No.

5 Q. -- forhaemophilia. You state there that you were
6 considered to be a pre-operative haemorrhage risk and
7 that you didn't haemorrhage but they still insisted on
8 administering Factor VIII in recovery despite the fact
9 that you were stable both before and after the
10 operation?

11 A. Yes.

12 Q. You say:

13 "I told the medical staff pre-operatively that
14 I did not want Factor VIII because I had never had any
15 bleeding problems my whole life."

16 I'm going to clarify some points in this. Look at
17 WIT0010623. It's a letter from Dr Willoughby to
18 Dr Forbes. It's dated 15 December 1981 and it's telling
19 him that:

20 We tested [you] when we heard that [you] were
21 having the sterilisation and found your Factor VIII
22 level to be 26 per cent. "At our suggestion she was
23 given 1,120 units of Factor VIII at the hospital prior
24 to the sterilisation and she made an uneventful
25 recovery."

1 I think you said in your statement that you thought
2 you had the Factor VIII in recovery, after the
3 operation?

4 A. Yes, it was after the operation.

5 Q. Are you sure about that? It couldn't have been before,
6 since that is suggested? Right?

7 A. Because Sister Wright had told me later that they sent
8 the Factor VIII over in a taxi for it to be administered
9 after I had the operation.

10 Q. I didn't catch the beginning?

11 A. Sister Wright said that they had sent the Factor VIII
12 over in a taxi so that I could have it after I was
13 operated on. I actually woke up and told them to remove
14 it from my arm, the Factor VIII.

15 Q. You say that you told them that you didn't want it. Why
16 didn't you want it?

17 A. I never needed it before. I just felt they were making
18 a mountain out of a molehill, that there was nothing
19 there to be treated. I had always been all right.

20 Q. Right. You said the Factor VIII was brought over.
21 Where was it brought over from?

22 A. It was sent over from Yorkhill in a taxi to the [REDACTED] in
23 [REDACTED].

24 Q. So were you given any information about Factor VIII at
25 that point?

1 A. No, no. They just said that because I was going into
2 hospital they wanted to check my levels to make sure
3 that I wasn't at risk.

4 Q. Right.

5 A. And I never heard any more about it until after I woke
6 up.

7 Q. You say that when you woke up, you were getting the
8 Factor VIII?

9 A. Yes.

10 Q. Right. So I take it then that there were no discussions
11 with you?

12 A. No.

13 Q. Were there any discussions with you before the surgery
14 about you having Factor VIII?

15 A. No, but they said I had signed a waiver saying any
16 treatment that was necessary they would administer.
17 I had signed that, to say if there was anything...

18 Q. Did they get the impression then that you were unhappy
19 that when you woke up you were getting Factor VIII?

20 A. Yes.

21 Q. Yes. This is probably an obvious question but I take it
22 you weren't warned of any risks of Factor VIII treatment
23 at that time?

24 A. No.

25 Q. Dr Willoughby notes in that letter that you made an

1 "uneventful recovery". From what you say, if we go back
2 to paragraph 7 of your statement, immediately following
3 your surgery you had acute jaundice for a week?

4 A. Yes.

5 Q. And it was your GP who treated you for this --

6 A. Yes.

7 Q. -- at the time. You say:

8 "The above-noted batch of Factor VIII was withdrawn
9 from use."

10 We don't actually have a note of the number there.
11 How do you know that the Factor VIII was withdrawn from
12 use?

13 A. Because, after I had been back up to the hospital again,
14 the sister told me that it was withdrawn as a safety
15 precaution.

16 Q. Was that because --

17 A. Because I had taken jaundice.

18 Q. Right. And you say you were back up at the hospital.
19 Was that for a review appointment after your surgery?

20 A. No, that was back up at Yorkhill for [REDACTED].

21 Q. Right. And you didn't think there was a link between,
22 at that time, your jaundice and the Factor VIII?

23 A. No.

24 Q. Because you hadn't been warned about the risks
25 associated with Factor VIII and there was a suggestion

1 that you would be put in isolation, you managed to be
2 able to remain at home --

3 A. Yes.

4 Q. -- while the yellow phase, as you say over the page, ran
5 its own course.

6 And you also felt extremely nauseous at that time?

7 A. Yes.

8 Q. If we look at a document WIT0010620, this identifies
9 the source of your infection with the Hepatitis C virus.
10 It's a letter from Anna Pettigrew to Dr Lowe in 1988 and
11 is in relation to further surgery which you were going
12 to have in 1988. The first paragraph mentions your
13 Factor VIII level of 26 per cent and says that at the
14 time of your operation in 1981 you received Armour
15 Factor VIII, 2,800 units, batch number VC2103, as
16 haemostatic cover for sterilisation and it identifies
17 there that you developed jaundice and were investigated
18 by your GP and that Hepatitis A and B markers were
19 negative:

20 "but I do not think there has been any subsequent
21 follow up on liver function tests or other viral
22 markers."

23 Did you get -- after having jaundice, was there any
24 follow-up in relation to you having had jaundice?

25 A. Not in relation to me having had jaundice, but they

1 decided, when I was going in to have a hysterectomy,
2 that they wanted to give me a Hepatitis B.

3 Q. Right, and that was the hysterectomy in November 1988,
4 which is mentioned in the second paragraph?

5 A. Again I was supposed get that operation done in [REDACTED]
6 but Dr Lowe, at the Royal, had decided that I should get
7 it done there just in case I haemorrhaged because it's
8 a much more serious operation than being sterilised.

9 Q. Right. Then were you given synthetic Factor VIII?

10 A. Yes, they gave me DDAVP because they thought I might
11 have an allergic reaction to Factor VIII.

12 Q. Right. Was that because of your jaundice at the time in
13 1981?

14 A. Yes.

15 Q. Right. So when you underwent further surgery
16 in November 1988, you were given DDAVP cover, and
17 I think, if we go back to your statement at paragraph 9,
18 which is 0031, you say:

19 "Although my Factor VIII level is low (40 iu/dl), it
20 has not caused me any problems. Since 1981 I have had
21 synthetic DDAVP cover for all subsequent major and minor
22 surgery."

23 You mention the hysterectomy surgery in 1988 and how
24 Dr Willoughby referred you to the adult haemophilia unit
25 at GRI to be registered as a carrier and you mention

1 there that you attend the haemophilia unit for yearly
2 routine blood tests?

3 A. Yes.

4 Q. Do you continue to do that?

5 A. Yes, I do.

6 Q. The last sentence:

7 The Haemophilia Unit confirmed that [you] have
8 an abnormal banding pattern, "which shows that I'm
9 a carrier of the distal Factor VIII/intron 22 gene
10 rearrangement."

11 Is that the explanation for your low Factor VIII
12 levels?

13 A. Yes.

14 Q. Now, you say further on in your statement that it wasn't
15 until 1991, ten years later, that you found out that you
16 had acquired Hepatitis C.

17 A. Yes.

18 Q. So in between that time, had you recovered from your
19 episode of jaundice?

20 A. Yes.

21 Q. And you were just dealing with other matters actually in
22 relation to -- ██████████ in that period was diagnosed
23 with HIV. So you had other things on your mind?

24 A. Yes.

25 Q. And I think, if we can just conclude your story of your

1 Hepatitis C, it's referred to in paragraph 19 of your
2 witness statement, which is 0036, when you tell us that,
3 as you were dealing with the challenges of bringing up
4 a son with HIV, in 1991 the SNBTS wrote to you and asked
5 you to come to a meeting at their Glasgow offices. Had
6 you given blood before then?

7 A. Yes, I had given blood a couple of weeks before that.

8 Q. Was that at a local blood transfusion centre?

9 A. Yes, it was a mobile one.

10 Q. A mobile one?

11 A. Yes.

12 Q. And you were told that they had tested your donation to
13 find that you were Hepatitis C-positive, you were told
14 to stop donating blood and not to consider donating your
15 organs. You were advised that Hepatitis C was
16 transmitted to you from the Factor VIII given to you in
17 1981. Who told you that?

18 A. It was suggested to me by the blood -- you know, did
19 I take drugs, had I had any medication. It was
20 suggested it could have come from that.

21 Q. Right. Did anybody ever subsequently confirm to you
22 that it did come from that?

23 A. No.

24 Q. And you point out that, had you not been a blood donor,
25 you feel you might not have found out?

1 A. I don't think I would have found out.

2 Q. And what information were you given, at the time you
3 were told that you had the Hepatitis C virus, about the
4 virus?

5 A. I wasn't told anything about it --

6 Q. Right.

7 A. -- apart from the fact that I shouldn't give blood again
8 and I shouldn't donate my organs. They just -- they
9 never gave me any information and, if they did, I think
10 I was in too much of a shock to take it in.

11 Q. It must have been a very shocking meeting for you. Did
12 you have any idea, when you were asked to go to that
13 meeting, that you were going to be told --

14 A. No idea at all.

15 Q. What was suggested for what should be done in relation
16 to your Hepatitis C? Did the doctor at the SNBTS
17 suggest that you go and see your GP?

18 A. Well, I went to my GP. Yes, he did, he suggested I go
19 and see my GP and that's what I done.

20 Q. That's what you did. Okay. We can see, if we move
21 further down to paragraph 20, that you did go and see
22 your GP, who referred you to Dr Mill's clinic at
23 Gartnavel General in Glasgow, and at that point he
24 advised you to start interferon treatment?

25 A. Yes.

1 Q. And you started that fairly quickly after your diagnosis
2 with Hepatitis C in 1991?

3 A. Yes, that's right.

4 Q. It was a 12-week course and you tell us there that it
5 involved injecting interferon subcutaneously three times
6 a week.

7 A. The programme would have lasted longer but, because
8 I showed a negative response -- if nothing happens
9 within the first 12 weeks, then you stop the treatment,
10 and nothing happened.

11 Q. Right, so they were obviously monitoring you?

12 A. So -- yes. So I was removed from the programme.

13 Q. Right. So was the plan that -- the course would be how
14 long if you had shown --

15 A. I think it's the same as the one I have just --
16 48 weeks, it would have lasted.

17 Q. And you suffered the side effects of the treatment?

18 A. Oh, yes.

19 Q. Would you tell us about those at that time?

20 A. At that time it felt -- I used to take it at night and
21 then just go to my bed because I just felt so ill after
22 taking it. I felt flu-like symptoms. My bones were
23 sore and I just got so tired.

24 Q. Right. Were you working at the time?

25 A. Yes.

1 Q. Did you manage to keep working?

2 A. Yes, because of the time that I took it; I used to take
3 it just after tea time and then just go to my bed.

4 Q. Okay. Then you say that, because the monitoring while
5 you were having the treatment showed that you weren't
6 responding to it, you had to stop it at 12 weeks.

7 A. Yes.

8 Q. That must have been very disappointing for you.

9 A. It was very disappointing.

10 Q. Particularly after going through the side effects of the
11 treatment. What were you told by the doctors would
12 happen next?

13 A. They told me that they were always experimenting and
14 trying to bring up new ways of treating it and if they
15 ever bought anything, then they would get in touch with
16 me again.

17 Q. Right. Did you carry on attending the liver clinic for
18 check-ups? I think you say you did?

19 A. I did continue, yes.

20 Q. And that was once a year?

21 A. Yes.

22 Q. And it was too risky, given your Factor VIII count, to
23 have a liver biopsy?

24 A. Yes, they didn't want to do it because of the risk
25 factor involved.

1 Q. Have you ever had a liver biopsy?

2 A. No, I have had an ultrasound.

3 Q. Right. I think you have had treatment again?

4 A. Yes, it started last year.

5 Q. Right. What was that treatment with?

6 A. That was with interferon again and ribavirin.

7 Q. Right, and how long did that treatment last?

8 A. 48 long weeks.

9 Q. And would you like to tell us about the side effects of
10 that treatment?

11 A. The side effects were pretty much the same: Very tired;
12 I felt sick a lot of the time. I must have been an
13 absolute nightmare to live with because I felt as if
14 I was living a nightmare. I think my husband could
15 probably testify to that. But we got through it.

16 Q. Okay. You have had a check since that treatment?

17 A. Yes, I have.

18 Q. What did that show?

19 A. I had check -- well, they constantly check you through
20 the treatment to make sure that you are responding.
21 After the 48 weeks it shows that I'm negative for
22 Hepatitis C.

23 Q. Good.

24 A. I have to go back in October again for another check but
25 they have told me that even though it's negative now, it

1 could still reappear, because it could just hide
2 somewhere.

3 Q. Right. Do you still feel you are suffering the effects
4 of that treatment?

5 A. I'm starting to feel a bit better now. It's about six
6 weeks I have been off it now. So I have started to come
7 back to feeling a bit more like myself.

8 Q. Thank you for telling us about that.

9 I think we will return now to [REDACTED]'s story.
10 If we go back to paragraph 10 of your witness statement,
11 which is at 0031. You tell us that you adopted another
12 child in December 1982?

13 A. Yes, that was the reason that I became sterilised in the
14 first place. Because we were so young, I don't think
15 the councils thought that we were serious about it,
16 about adopting; me not having any more children due to
17 the haemophilia.

18 Q. So you had the sterilisation and then you were able to
19 adopt?

20 A. It wasn't quite like that. I decided -- we both decided
21 that we weren't going to have any more children and
22 rather than something happen accidentally, we made the
23 decision it was better for me to be sterilised because
24 it was me that produced the haemophiliacs.

25 Q. So the decision not to have any further children was

1 solely based on the risk of having another child with
2 haemophilia?

3 A. Yes.

4 Q. So [REDACTED]'s brother was adopted in [REDACTED]?

5 A. Yes.

6 Q. He was aged 18 months at that time?

7 A. Yes.

8 Q. So [REDACTED] would have been about seven then?

9 A. Yes.

10 Q. You are saying that that same year you were told in
11 a hospital corridor in Yorkhill that [REDACTED] had
12 HIV?

13 A. Yes.

14 Q. In 1982 there weren't tests for the HIV virus so could
15 it have been later? Could it have been in 1984/1985 --

16 A. It could have been because trying to think back years --
17 knowing that you were told, you don't associate a year
18 with it. It could have been 1984.

19 Q. It could have been 1984, could it have been 1985?

20 A. I don't know.

21 Q. It obviously is a long time ago.

22 A. Ah-huh. All I can tell you is it did happen.

23 Q. It did happen and did it happen in a hospital corridor?

24 A. It happened in Yorkhill.

25 Q. In Yorkhill?

1 A. Yes.

2 Q. And you say that one of the haemophilia doctors,
3 Dr Anna Pettigrew, came out and said in passing that she
4 was sorry it was taking so long for you to be seen by
5 one of the doctors but there were a lot of children
6 there who had HIV and that [REDACTED] was one of them?

7 A. Yes. You have got to understand that there was no
8 malice in it. We had known her -- we have known her for
9 a lot of years. So she was more like a friend and
10 I don't think it was intended to be anything else but
11 just giving me a bit of information.

12 Q. Right. Can you remember why you were at that
13 appointment?

14 A. It was just a normal clinic.

15 Q. Was it a normal clinic appointment?

16 A. Yes.

17 Q. So do you think you were waiting to go into the clinic
18 appointment?

19 A. Yes.

20 Q. Yes. So where would you have been sitting?

21 A. In the corridor.

22 Q. In the corridor?

23 A. Yes.

24 Q. And was Dr Pettigrew seeing the people who were coming
25 to the clinic appointments?

1 A. Yes, she was. She was seeing the children along with --
2 I think it might have been Brenda Gibson at that point.

3 Q. Right.

4 A. I'm not sure.

5 Q. Okay. Did you know then that [REDACTED] had been
6 tested for the virus?

7 A. No.

8 Q. No.

9 A. We knew they took blood tests -- they took blood all the
10 time -- but we didn't know that they were checking him
11 out for the virus.

12 Q. Right. If we carry on reading:

13 "I don't know when they tested [REDACTED] for HIV.
14 I don't know when he became infected. No one confirmed
15 this to me. At the time that we found out that
16 [REDACTED] had been infected with HIV, no one explained
17 anything about HIV to us or how it would affect
18 [REDACTED]'s health. We weren't told to take any
19 precautions. I went home in shock and told my
20 husband. Our world crashed down around us."

21 So after Dr Pettigrew had walked past and apologised
22 for the delay and explaining why, did you then go in and
23 see Dr Pettigrew?

24 A. Yes.

25 Q. And so was it her who told you more formally than the

1 comment in the --

2 A. Really, to be honest, I can't remember who told me more
3 formally.

4 Q. Okay.

5 A. I think it very well could have been. It very well
6 could have been.

7 Q. Right. Your recollection is that the moment you found
8 out that your son had acquired HIV was when you were
9 sitting in the corridor waiting to go into your
10 appointment?

11 A. Yes, it was.

12 THE CHAIRMAN: Christine, were you alone in the corridor or
13 were there other family groups there?

14 A. At that point I was alone in the corridor.

15 THE CHAIRMAN: Alone?

16 A. Yes.

17 THE CHAIRMAN: Did you see other family groups that day?

18 A. Yes.

19 THE CHAIRMAN: Before you went in or after or what?

20 A. When I was coming out there were other ones sitting
21 waiting.

22 THE CHAIRMAN: Were these people you knew?

23 A. Yes.

24 THE CHAIRMAN: There is really quite a community of parents?

25 A. Yes, we were.

1 THE CHAIRMAN: Was anything said at that stage or did you
2 just go away home?

3 A. I just went home.

4 MS PATRICK: It must be difficult for you to remember. It's
5 a long time ago and it must have been a great shock to
6 you at the time.

7 A. It was.

8 Q. Can you remember if you were warned of a risk of
9 secondary infection?

10 A. No, I can't remember.

11 Q. Were you given any information about how he might have
12 acquired the virus?

13 A. No.

14 Q. No. Can you remember what was to happen after that?
15 Was the plan that [REDACTED] would continue to be
16 monitored?

17 A. Well, they just said that they would keep an eye on him.
18 They didn't know what the effects of it would be and
19 they would just keep a close eye on him to make sure
20 that everything stayed as it was then.

21 Q. So you were on your own, were you, with [REDACTED]?

22 A. Yes.

23 Q. You went home and told your husband?

24 A. When he came home, yes.

25 Q. Looking back, can you remember, what did you know about

1 the virus?

2 A. I didn't know anything.

3 Q. At that time?

4 A. I didn't know anything about it.

5 Q. Was it a totally new thing for you to hear about?

6 A. No, we heard about it, that HIV was in Africa and it was
7 affecting the gay community but that was about all. We
8 didn't know what the effects of it were, or, you know,
9 how they are exposed to it.

10 Q. So you were told he had the virus. You don't remember
11 being told anything about it?

12 A. No.

13 Q. Do you remember being told how he had acquired the
14 virus?

15 A. No.

16 Q. So did you have any idea how he got the virus?

17 A. No, we didn't make a connection at all. We didn't.

18 Q. Did you think at that time it was just one of these
19 things that had happened?

20 A. Yes, we did.

21 Q. So when was it that you found out that it had been the
22 Factor VIII which had given him --

23 A. I can't remember. I really can't remember.

24 Q. If we could go back to your statement, to paragraph 11,
25 you obviously went home and relayed the news to your

1 husband and you say your whole world crashed down around
2 you?

3 A. Yes.

4 Q. In paragraph 11 you talk about the plans to you had
5 made, I think, before his diagnosis?

6 A. Yes.

7 Q. Was it to adopt the natural sibling of [REDACTED]'s
8 brother?

9 A. Yes.

10 Q. You were worried that by having two natural brothers,
11 [REDACTED] would feel as though he was being pushed out
12 and you didn't think it was fair to bring another baby
13 into the house, given that [REDACTED] was newly
14 diagnosed with HIV. You didn't know the long-term
15 effects of HIV and you didn't know what was going to
16 happen:

17 "That is why we had to stop the adoption process."
18
19
20

21 A. Yes.

22 Q. So would it be fair to say that you felt just a great
23 deal of uncertainty?

24 A. We just didn't know anything, but we just didn't want to
25 change what we had. We had to try and stabilise what we

1 had and not add any more factors into it.

2 Q. How did your husband react when you told him about the
3 virus, that [REDACTED] had HIV?

4 A. Just exactly the same as I did.

5 Q. Total shock?

6 A. Total shock.

7 Q. Were you offered any counselling or support --

8 A. No.

9 Q. -- at the time?

10 A. Nothing.

11 Q. So did you have anybody to speak to about it?

12 A. No. Our GP, when it happened, advised us not to tell
13 anyone because we were running our own business, we were
14 [REDACTED] and we worked in a small community,
15 that he felt that we might be ostracised. He also told
16 us anything relating to [REDACTED], if it came through
17 the post to him, he would put it in a sealed file that
18 only him and the other partners could see. So it was
19 very much, "Keep it to yourself and don't mention
20 anything".

21 Q. How did your GP find out? Did you tell him?

22 A. He was informed by a letter from the doctor.

23 Q. So he advised you to keep it to yourselves and he sealed
24 [REDACTED]'s case notes so that only the senior
25 partners in the practice would see them?

1 A. Yes, because people that lived near us worked there.

2 So -- I mean, the medical files in a doctor's surgery
3 are open to anyone that does work there.

4 Q. So he sealed the records so only the senior partners at
5 the practice would see them --

6 A. Yes.

7 Q. -- and no one, like, for example, reception staff or
8 anybody like that, would be able to.

9 You talk about that in paragraph 16 of your
10 statement, which is WIT0040034, when you tell us about
11 this. It's about the fourth or the fifth line up:

12 "I think that the doctor probably thought he was
13 doing the right thing at the time by keeping it secret
14 but the secrecy was probably one of the worst things."

15

16

17

18 You say there that the only person you told within
19 your family was your brother?

20 A. Yes.

21 Q. If we go to the top of that paragraph, you say:

22 "To this day very few people know that [REDACTED]
23 had HIV."

24

25

1

2 You obviously didn't tell your mother?

3 A. No.

4 Q. You didn't tell your husband's family?

5 A. No. The only reason that -- I have four brothers and

6 the only reason one of them knows is because he is HIV

7 as well.

8 Q. Right. Was he already HIV at the time you found out

9 about [REDACTED]?

10 A. Yes.

11 Q. Yes.

12 A. I think it worked out he found out about roughly the

13 same time as we did about [REDACTED], but he was down

14 in Oxford for a lot of years.

15 Q. Right. So that was one person that you can speak to?

16 A. Yes.

17 Q. I think you also mention that you felt that the hospital

18 staff also encouraged you to keep quiet about

19 [REDACTED]'s diagnosis with HIV?

20 A. Yes.

21 Q. Yes. In what way did they encourage you? Did they

22 suggest to you that it was a good idea to keep it to

23 yourselves?

24 A. They said they didn't want people panicking over it or,

25 you know, maybe shunning us, us being ostracised.

1 I think it was just the way it was then, that they
2 didn't know anything or they didn't know as much as they
3 do now and rather than cause panic...

4 Q. Right. I think you also say at the end of paragraph 13,
5 which is 0033, that as you continued to attend your
6 routine haemophilia clinics, the doctors who worked at
7 Yorkhill were very reluctant to talk about the virus
8 with you, which left you wondering what was going on?

9 A. Yes.

10 Q. So am I right in thinking that you were given the
11 information that [REDACTED] had HIV but from your
12 perception you weren't given much more and you were
13 encouraged not to speak about it by all the health
14 professionals --

15 A. Yes.

16 Q. So in paragraph 14 you tell us how isolated you and your
17 husband felt and how your husband drowned out the bad
18 news by drinking too much alcohol, and that you both
19 shut yourselves away?

20 A. Yes.

21 Q. You stopped going out with friends and in that process
22 lost a lot of friends, and you didn't feel you could
23 tell anyone and you think that your friends thought that
24 you were going weird and anti-social because you
25 obviously withdrew into your family unit?

1 A. Hm-mm.

2 Q. Even when you did try to go out with friends, you would
3 find yourselves getting morose about things --

4 A. Yes.

5 Q. -- and presumably feeling that you had a big secret that
6 you couldn't talk about?

7 A. Yes.

8 Q. You say:

9 "The only person that I could speak to about
10 ██████████'s HIV was my husband and vice versa. The
11 stress of only being able to speak to each other built
12 up inside us and we took it out on each other."
13
14
15
16 This caused you to argue and you felt that the
17 biggest thing was the stigma, and you asked yourselves
18 constantly why you should have stigma. You felt you
19 hadn't done anything wrong.

20 A. We hadn't done anything wrong but we were thinking about
21 ██████████ as well.

22 Q. That might be a good time?

23 THE CHAIRMAN: Do you want wee break? We will have a break.
24 (10.49 am)

25 (Short break)

1 (11.15 am)

2 THE CHAIRMAN: Christine, if there is any wee bit of fact
3 that you can get ██████ to help you with, just ask.

4 A. Thank you.

5 THE CHAIRMAN: But you know, you will probably feel better
6 doing as much of it as you can but it is a great help
7 if, between you, you can make sure that we get the most
8 accurate dates and facts.

9 A. Okay, thank you.

10 THE CHAIRMAN: Yes?

11 MS PATRICK: Thank you.

12 Christine, I think, before the break we were at the
13 stage just after you found out about ██████'s
14 diagnosis with HIV.

15 A. Yes.

16 Q. And the impact of this on you and your husband. Would
17 you look at paragraph 13 of your statement, which is
18 ending 0033. You tell us that although initially you
19 didn't know much about the virus. Within a few months
20 of finding out that ██████ had it, you began to
21 realise how serious it was.

22 A. Yes.

23 Q. The information that assisted you with this was what was
24 coming out in the media. Was that what you saw in
25 newspapers?

1 A. Yes. What you saw in newspapers, what you heard on the
2 television.

3 Q. Okay. You say there were all sorts of stories in the
4 paper at that time and there was more a link to gay
5 people and drug users in America --

6 A. Yes.

7 Q. -- in relation to the virus, and it was being referred
8 to at that time as the "gay plague"?

9 A. Yes.

10 Q. You still didn't know really the prognosis for
11 [REDACTED] at that time --

12 A. No.

13 Q. -- having the virus?

14 A. No, we didn't.

15 Q. Okay. You tell us in paragraph 15 of your statement,
16 which is the next page, ending 0034, that you didn't
17 tell [REDACTED] for some years about his HIV diagnosis.
18 Were you given any advice in reaching that decision?

19 A. No, we weren't given any at all. My husband was saying
20 it was because he might become sexually active we
21 decided it might be a good time then.

22 Q. At the time you found out his diagnosis you felt it
23 wasn't appropriate that he knew about it and he carried
24 on living his life, you say there, as an active boy who
25 had haemophilia.

1 A. Yes.

2 Q. He obviously enjoyed his sports?

3 A. Yes.

4 Q. Despite his haemophilia. So he was able to play
5 football and ride his bike. What other things did he
6 enjoy doing?

7 A. He was in the Scouts.

8 Q. Right.

9 A. He enjoyed the Scout movement as well. And he just used
10 to go out with his friends.

11 Q. So he was a sociable boy?

12 A. Yes, very.

13 Q. You say there that you didn't tell his school. Was that
14 on the advice of anyone or was that your own decision?

15 A. We felt that we didn't want him to be ostracised at
16 school and we had enough problems trying to get him
17 admitted into a normal school because of his
18 haemophilia.

19 Q. Did you?

20 A. Yes. We had to jump through hoops with them. They
21 wanted to put him into a special nursery when he was a
22 baby. We had to promise the school that any time
23 anything happened we would respond to it immediately.
24 Even when he went away on a primary 7 trip with the
25 school, they wouldn't let him go unless I went with him.

1 Q. I saw that from the medical reports, that you had to
2 accompany him sometimes on medical (sic) trips?

3 A. Yes. That's right.

4 Q. Was that the case even if there was a school nurse
5 there?

6 A. Yes, because they weren't equipped to deal with it. So
7 that was part of the plan, that [REDACTED], if anything
8 ever happened to him, all they had to do was phone us
9 and we would respond and deal with it there and then.
10 So it just made it even more apparent that anything
11 related to blood, how important it was for them to glove
12 up before they even touched him.

13 Q. So did you have to provide a lot of support to the
14 school?

15 A. Yes.

16 Q. What kind of support was that?

17 A. Before he started school the nursing staff, I think,
18 Dr Pettigrew, and one of the senior nurses, went to the
19 school to tell them about haemophilia because they
20 hadn't dealt with it before and they reassured them that
21 he could be treated as a normal pupil.

22 Q. Right. So they assisted you in persuading the school
23 that they could cope with a boy with severe haemophilia
24 like [REDACTED]?

25 A. Yes, hm-mm.

1 Q. And did you have the same struggle in relation to
2 secondary school?

3 A. Well, this was secondary school, wasn't it? (Addresses
4 husband)

5 With secondary school it was fine there because he
6 went through primary school without a problem. They
7 were prepared to accept him as he was. So we didn't
8 want the stigma of HIV possibly causing him to be sent
9 somewhere else.

10 Q. I think there was a worry some time because there was
11 a spell when [REDACTED] was having nose bleeds --

12 A. Yes.

13 Q. -- at school. Obviously this was a concern, I think, of
14 your doctors in relation to him having these at school,
15 and this is mentioned in a document, WIT0040071. This
16 is Dr Pettigrew telling a consultant ENT surgeon that
17 [REDACTED] was having recurrent, profuse nose bleeds,
18 which are controlled by Factor VIII and tranexamic acid.
19 They are very troublesome, particularly as he is high
20 risk, and they were anxious about this at school?

21 A. Yes.

22 Q. Did you know if schools had procedures in place for
23 dealing with bleeds at that time?

24 A. Yes, they had blood kits in the school. It's just all
25 the things that you need to deal with blood so that you

1 don't get contaminated.

2 Q. So they had --

3 A. Well, at that age [REDACTED] knew that he could deal
4 with it himself and no one ever went near him.

5 Q. Right. So did he know at that stage, even though he
6 didn't know about his HIV status, to try and keep his
7 bleeds to himself?

8 A. Yes, he was always taught that from a very early age.

9 Q. Right. So you said that from the time of [REDACTED]'s
10 diagnosis with HIV, until he found out about it, he
11 continued to attend the haemophilia clinic?

12 A. Yes.

13 Q. Were there more appointments or did it just carry on as
14 it had done before then?

15 A. I think -- it just carried on as normal, or as normal as
16 normal could be.

17 Q. I think you have said that you felt that not a lot was
18 said about HIV at the time?

19 A. No, they seemed very reluctant to talk about it.

20 Q. Did you ask them how he was in relation to the virus?

21 A. They just said that everything was fine. I think it was
22 lack of knowledge at that time, that no one really knew
23 what was going to happen.

24 Q. Right.

25 A. You know, what the next stage would be, if any.

1 Q. Okay. Going back to your witness statement,
2 paragraph 18, which is 0035, you say, in about the third
3 line, that he was asymptomatic to HIV for many years
4 until he was 14 years old?

5 A. Yes.

6 Q. It appears from the medical records that you are aware
7 the Inquiry have recovered, that [REDACTED] may have
8 had some symptoms of the HIV virus before then?

9 A. No, I didn't know.

10 Q. I thought I would refer you to these. The first of this
11 is in December 1985, when [REDACTED] would have been
12 10 years old --

13 A. 11.

14 Q. Eleven. WIT0040068. Can we go to the end? This is
15 a letter from Dr Pettigrew to your GP,
16 dated December 1985, talking about a haemophilia clinic
17 appointment recently and saying:

18 "He has been well apart from recent respiratory
19 tract infections" and his hearing has been poor of late.

20 It mentions in the third paragraph what we have just
21 been discussing, that he is doing well at school and is
22 going on a school trip to Wales in the summer time.

23 I think the hospital staff had liaised with the school
24 about this and given them information. It says:

25 "However they were naturally rather anxious about

1 taking [REDACTED] and it was felt that the best
2 compromise was for [you] to accompany the party on the
3 trip."

4 A. Yes.

5 Q. So you went on a school trip to Wales?

6 A. Yes.

7 Q. If we move on to WIT0040070, this is once again
8 a letter from Dr Pettigrew to your GP in respect of a
9 clinic appointment in December 1986. It discusses
10 initially how he is doing from a haemophilia point of
11 view. Then half way down the first paragraph it says:

12 "His general health remains good. In particular he
13 has a good appetite, his weight has increased and he is
14 an active boy. He has had no sweats, fever, rashes or
15 diarrhoea. However, he has had a persistent cough since
16 his last visit in October. This does however seem to
17 be subsiding now."

18 I think he had started at his new school in that
19 year?

20 A. Yes, he went to high school.

21 Q. And had settled well and had no problems at school. Did
22 he have any difficulties at school in relation to his
23 haemophilia?

24 A. No.

25 Q. No. Did he feel different from the other children

1 there?

2 A. No.

3 Q. No. Moving on to June 1987, WIT0040072, this is

4 a referral by Dr Pettigrew of ██████████ to

5 a dermatologist in relation to an unsightly and large

6 wart on his left mid finger. Do you remember this?

7 A. Yes.

8 Q. Yes. Had ██████████ had warts before then?

9 A. He had, yes, but they were treated.

10 Q. They were treated.

11 A. But this one just seemed to --

12 Q. This one didn't --

13 A. It gave him discomfort.

14 Q. Right. As you will see, it's highlighted in the second

15 paragraph:

16 "As I have mentioned, he is a high risk patient and

17 we would advise all precautions to avoid contact with

18 blood."

19 The response to this is WIT0040073. That's

20 Dr Roberts replying, saying he has made the assumption

21 that he is HIV positive from the hint that was given to

22 him in the previous letter and he says:

23 "In my opinion, warts in such patients would be best

24 left alone. The fact they are HIV positive does not

25 prevent them mounting an immune response to the wart

1 virus so the warts will go away."

2 So he recommends that the best thing to do is to
3 ignore them. I think around this time, it was touched
4 on in one of the earlier letters, [REDACTED] was
5 developing problems with his hearing and glue ear. Is
6 that right?

7 A. Yes.

8 Q. Were you told at all if that was linked or caused by his
9 HIV?

10 A. We had done a trip to Orlando and we assumed that it was
11 from flying because of the long distance flight, and the
12 flight back wasn't comfortable and it was after that he
13 started to develop his hearing problems. We just
14 associated it with the flight.

15 Q. So no one ever told you that it might be linked to his
16 HIV?

17 A. No.

18 Q. And did he get grommets inserted?

19 A. Yes, he did.

20 Q. He did. Can we move on to November 1987, WIT0040074?

21 This is, once again, a letter after a clinic appointment
22 and it mentions that [REDACTED]'s general health has
23 been good apart from recurrent tonsillitis. So it's
24 painting a picture of [REDACTED] beginning to get
25 infections of tonsillitis, difficulties with his ears,

1 and it mentions there he has had no recurrence of mouth
2 ulcers but he is developing acne and also had recurrent
3 staphylococcal in his ear lobe. But once again they are
4 monitoring him.

5 If we move on to WIT0040076, this mentions his
6 recurring tonsillitis. If you go about half way down the
7 first paragraph, his general health has been good. Once
8 again, no fevers, sweats, vomiting or diarrhoea. He has
9 developed facial acne, which Dr Pettigrew does not think
10 is related to his HIV, and mention again of recurrent
11 episodes of tonsillitis. And he currently has an upper
12 respiratory tract infection with associated nose bleeds
13 in the last few days.

14 But on examination, you will see in paragraph 3:

15 "He appeared well and there was no
16 lymphadenopathy."

17 Further down, some blood tests show that he has
18 a healthy T4/T8 ratio, which is one of the things they
19 use to monitor the immune system.

20 Moving to October 1988, WIT0040078, this is
21 a letter once again from a dermatologist. I think
22 [REDACTED] is having difficulty again with hand warts
23 and the dermatologist is saying:

24 He has very troublesome hand warts. They are
25 extremely common and they may be unrelated to his HIV

1 status, however, equally this group of patients may well
2 get a higher instance of hand warts.

3 And he is treated with liquid nitrogen.

4 Moving on to April 1989 -- how old would [REDACTED]
5 have been at this point?

6 A. 14.

7 Q. Yes. He is admitted to hospital for a night. This is
8 a letter from the haematology registrar to his GP,
9 dated April 1989, and he has had a four-day history of
10 a sore throat, facial pain with facial swelling and
11 nasal discharge, and a temperature. He was given
12 antibiotics and these symptoms settled and he was
13 allowed home. Did [REDACTED], while he was at school,
14 start to have spells of needing to go into hospital more
15 frequently?

16 A. Yes, he did. They tended to be chest/throat infections.

17 Q. How did that affect his schooling?

18 A. He was able to catch up. He was quite switched on with
19 what he was doing in school. So it didn't affect him
20 badly.

21 Q. No.

22 A. If there was anything he had to do, one of his friends
23 that lived two doors down would bring homework home for
24 him, and he was able to do it in the house and [REDACTED]
25 would take it back to school for him.

1 Q. So he just got on and dealt with it?

2 A. Yes.

3 Q. In paragraph 18 of your statement, which is
4 WIT0040035, you tell us what it was like for
5 [REDACTED] when he was an inpatient in Yorkhill after
6 he was diagnosed with HIV?

7 A. The first time he was admitted to hospital after he had
8 HIV, he was put in a side room.

9 Q. I think this is what you will see. If you have a look
10 at paragraph 18, about six or seven lines down, when he
11 went into Yorkhill. Do you have this statement in front
12 of you?

13 A. Yes.

14 Q. So you are telling us that he was put into a side room?
15 This is the first time.

16 A. Yes, he was put into a side room, the nursing staff went
17 in with masks, gloves and gowns on. Any food that he
18 was given was put -- was scraped into a disposable dish.
19 He dropped a pencil outside the door and the teacher
20 refused to pick it up and give it him back. Everything
21 was covered in polythene; the television, all the
22 equipment was all covered in polythene. I don't know
23 how he felt about it but we were absolutely shocked.
24 Regarding the pencil, my husband was there that day it
25 happened and he complained to the nursing staff who said

1 they were very sorry, it shouldn't have happened, it
2 wouldn't happen again. But to treat him like an animal
3 and put his food into a dish...

4 Q. Did anybody give you an explanation for any of that?

5 A. They said they were just being safe. So after that we
6 used to take his meals up for him. So he could have
7 a meal as a normal person rather than eating it out of
8 this disposable dish.

9 Q. Did that improve as time went on?

10 A. Yes, it did improve. I think because so many parents
11 complained about the way their children were being
12 treated. They didn't know -- none of the children were
13 told that they were HIV positive. So this was
14 a complete turnaround from the way they had been treated
15 before.

16 Q. So did you see other children being treated there in the
17 same way?

18 A. Yes, other haemophiliacs in the same situation were
19 treated the same way.

20 Q. I take it at that time [REDACTED] didn't know about his
21 diagnosis with HIV?

22 A. No.

23 Q. So it must have seemed a very odd thing to him to be
24 happening?

25 A. Yes, it did.

1 Q. But you say you don't know how he felt about it?

2 A. No, [REDACTED] was a boy that just took everything in
3 his stride.

4 Q. Moving on to when [REDACTED] did find out about his
5 diagnosis, you tell us about this in paragraph 15 of
6 your statement, which is WIT0040034, and half way down
7 that paragraph you say:
8 "In 1989 we ..."
9 I presume that's you and your husband?

10 A. Yes.

11 Q. "... made the important decision to tell [REDACTED]
12 about his HIV status."

13 I think you have touched on it earlier, that you
14 were worried about him becoming sexually active. So you
15 felt it was right for him to know about his HIV status?

16 A. Yes.

17 Q. Your husband explained to him that he had contracted HIV
18 from infected Factor VIII. [REDACTED] burst into tears
19 and just asked when he was going to die. He then pulled
20 himself together and did cope and just got on with his
21 life for a long time, which was hard for a vulnerable
22 14-year old.

23 A. Yes.

24 Q. Were you given any assistance from any of the doctors
25 or nurses --

1 A. No.

2 Q. -- about telling [REDACTED]?

3 A. No.

4 Q. Were you given any advice about when might be a good
5 time to tell him or how best to do it?

6 A. My husband was at a clinic with him that day and they
7 discussed it there and they said they thought he was at
8 an age where he should possibly be told. They wanted to
9 know if they would tell him and my husband decided, no,
10 he would wait until he came home and we would do it as
11 a family.

12 Q. Right. So was your husband offered any further support
13 in telling [REDACTED]?

14 A. No.

15 Q. And had [REDACTED] heard of HIV by this time?

16 A. Yes.

17 Q. So what did he know about it?

18 A. The only thing he knew about it was it was a gay plague.

19 Q. Right.

20 A. And the thing that worried him was when was he going to
21 die.

22 Q. Did you feel at that time that you had any more
23 information about the virus?

24 A. No. No more than what we had read or seen on the
25 television.

1 Q. So you had no further information at that time from the
2 hospital?

3 A. No, we didn't know what the long-term prognosis was at
4 that point.

5 My husband is saying it wasn't until he was about 16
6 they started to tell us about different counts, like the
7 T4 cell count, his blood counts; how that would show
8 that there was a change.

9 Q. So up until then you didn't know how any monitoring
10 could be done of his condition and it was really a case
11 of looking for symptoms?

12 A. Yes.

13 Q. Was there anybody that [REDACTED] was able to speak to
14 about this, other than yourselves?

15 A. I really, to this day, don't think he told anyone.

16 Q. So he didn't tell any of his friends?

17 A. No.

18 Q. None of your relatives?

19 A. No.

20 Q. You mention that there was a parent support group which
21 I think was set up by Christina Leach?

22 A. Yes, she was a social worker at Yorkhill.

23 Q. Were you attending that support group then?

24 A. Yes.

25 Q. What happened at that support group?

1 A. We just -- we were there to support each other. If
2 anyone had anything they weren't sure of, we all rallied
3 together with it but there was only a few of us but once
4 the boys started to die, then the support group very
5 quickly broke up.

6 Q. Did you find that helpful?

7 A. At the beginning we did, yes. At the beginning we did.
8 We had -- what was the surgeon's name?

9 Sam Galbraith, who was a surgeon at Yorkhill
10 Hospital but was also a MP, came to speak to us and he
11 said that years ago when he was doing brain surgery, it
12 was apparent there was something wrong, and he was sure
13 that that was what it was then. It was just a bubble
14 waiting to burst, as he described it.

15 Q. Right. So do you feel that that group was mostly
16 parents supporting each other?

17 A. Yes.

18 Q. Yes, rather than getting support from the hospital?

19 A. We had Christina Leach. She was there and Chris Murphy
20 on the odd occasion. She was a sister.

21 Q. Sorry, what was the name?

22 A. Christina Murphy. She was a sister up at Yorkhill who
23 dealt with the boys. She told us as much as she knew,
24 which really wasn't a lot.

25 Q. Was it a place for you to share information?

1 A. Yes.

2 Q. What everybody knew and what was happening with each
3 person's own child?

4 A. Yes.

5 THE CHAIRMAN: Do we have a date for the group?

6 MS PATRICK: Yes.

7 THE CHAIRMAN: Get it into the notes.

8 MS PATRICK: Can you remember when the support group
9 started?

10 A. My husband reckons it was about six months to a year
11 after the boys were diagnosed.

12 Q. Right.

13 A. He reckons it might have been about 1983/1984.

14 Q. Right. I think we were looking at the date when you
15 were told about his diagnosis, which may have been in
16 1984/1985?

17 A. Right. It was six months to a year after --

18 Q. Six months to a year after when you found out. Was
19 there anything similar for [REDACTED] or for other
20 boys?

21 A. No.

22 Q. Do you know if he spoke to any of the other boys?

23 A. If he did, he never told us and none of the other boys
24 told their parents either. So if they did, they kept it
25 to themselves.

1 Q. Right. So how did [REDACTED] deal with his diagnosis?

2 A. He was very quiet and withdrawn for a while after we
3 told him but then he just seemed to kind of pick himself
4 up. We tried to encourage him as much as we could, that
5 we just carry on as normal, and for a long time he was
6 pretty much back to normal.

7 Q. Did he talk to you at times about it?

8 A. Not really.

9 Q. No.

10 A. No.

11 Q. He just got on with his life?

12 A. Yes.

13 Q. You mention in your statement that [REDACTED] started
14 treatment for HIV around the time that you told him of
15 his diagnosis. If we look at paragraph 17 of your
16 statement, you say:

17 In 1989 when he "was 14 years old, he was asked by
18 Yorkhill if he wanted to participate in an HIV drug
19 trial for a new HIV treatment."

20 Going over the page:

21 He "had not been on any medication for HIV from the
22 date of diagnosis until this time. Half of those patients
23 who enrolled for the trial were given the drug, while
24 the other half were given a placebo. We were told that
25 the placebo wouldn't do him any harm and the drug was

1 intended to fight infections in the lung, although it
2 could cause ulcerations in the lung which they could
3 deal with."

4 You do not know how long this test went on for or
5 whether [REDACTED] received the placebo or the real
6 drugs. So it looks like that was a medication to try
7 and prevent an infection of the lung, which might have
8 been a common symptom of HIV?

9 A. Yes.

10 Q. Was this a trial initiated by the hospital?

11 A. Yes.

12 Q. It was? Can you remember which doctor was involved in
13 this?

14 A. With everything it was Anna Pettigrew that we dealt with
15 because she did have such a good relationship with the
16 boys.

17 Q. Right. How long roughly do you think the trial lasted?

18 A. We don't know because we were then being written out of
19 the picture, because he was then getting to an age where
20 he could make decisions for himself.

21 Q. Yes. How long did you keep going to appointments with
22 him?

23 A. I went every time he would like me to go. I think he
24 was about 16/17.

25 Q. Okay. It was usually you who went?

1 A. Whoever was available. One of us used to go.

2 Q. Okay. Did [REDACTED] have any side effects from taking
3 this drug?

4 A. I can't remember. No, no.

5 Q. Then you say in 1989 he was transferred from Yorkhill to
6 Glasgow Royal Infirmary in association with
7 Ruchill Hospital, which was a hospital designated for
8 treatment of children and adults with HIV and AIDS.

9 In fact it appears from the medical records that
10 initially there were joint clinics at Yorkhill, when
11 a doctor from Ruchill came to the haemophilia clinic.
12 Do you remember that?

13 A. I don't remember it. My husband does.

14 Q. Right. Then I think the medical records show that in
15 fact [REDACTED] was transferred to Ruchill Hospital in
16 1991?

17 A. Yes.

18 Q. When he was 16 years old?

19 A. Yes.

20 Q. Does that sound about right?

21 A. That is about right.

22 Q. If we look at WIT0040081, this is a letter from
23 Dr Gibson to [REDACTED]'s GP, mentioning the joint
24 clinic with Dr Campbell-Love from Ruchill Hospital. It
25 notes, about a quarter of the way down:

1 "His general health has been excellent with a marked
2 improvement in his hearing since having grommets
3 inserted." No recurrence of his sinusitis at present.
4 He appears to be asymptomatic from the point of view of
5 his HIV infection.

6 It says that:

7 "His CD4 cells remain at an acceptable level of 580 c/mm."

8 And the conclusion is that at present they consider
9 that there is no indication for antiviral therapy for
10 ██████████ but they will continue to monitor him.

11 Was this about the time that treatment for HIV was
12 first mentioned to you?

13 A. Yes.

14 Q. Or to ██████████?

15 A. I think it was around about the time when he moved to
16 Ruchill about the treatment with combination therapy.

17 Q. Yes.

18 A. He did the hyperbaric treatment as well, which caused
19 a great improvement in his chest.

20 Q. Is that a hyperbaric oxygen chamber?

21 A. Yes.

22 Q. Where did he do that?

23 A. He did that at Ruchill.

24 Q. Can you remember how old he was when he did that?

25 A. He was about 16 when he did that because he actually was

1 driving at that point. So he would have been over 16.

2 Q. Did he take himself for those?

3 A. Not for that. We took him for hyperbaric, but any
4 appointments he had after that, because he was classed
5 as an adult and he was mobile with his own car, he used
6 to take himself up to hospital.

7 Q. If we move on to October 1990, a letter, WIT0040082.

8 This is a further joint clinic appointment with
9 a DrDatta time from Ruchill Hospital and it notes about
10 a quarter of the way down:

11 [REDACTED]'s "general health is very good although
12 he has had a further episode of discharge from his left
13 ear, for which he attended as an emergency earlier this
14 week and was reviewed by the ENT surgeon" and drops were
15 prescribed which improved the situation.

16 He had gained weight:

17 "He denies any fevers, sweats, rashes,
18 diarrhoea, vomiting or anorexia. However, there is
19 a little concern that he might be having night sweats
20 as he is putting sheets out very regularly for washing
21 and his mother hasn't liked to press him on this point."

22 Was this a concern that you raised with the doctor?

23 A. Yes, it was. He was saying he wasn't having night
24 sweats and I was having all this extra washing.

25 Q. How was [REDACTED] when you asked him about things like

1 that? Was he quite private in that?

2 A. He was very private with it.

3 Q. Yes. So did you feel you were watching him and not
4 wanting to impose too much. It must have been
5 a difficult balance for you?

6 A. It was a difficult balance. We had a relationship that
7 if anything really worried him, we knew he would come
8 and talk to us but we never pushed him on it. We asked
9 him; if he denied it, that was fine, even though we had
10 other ideas on it.

11 Q. Right. It is noted that his CD4 cells have fallen in
12 number but have been stable for the last two months, and
13 once again the indications and the desirability of
14 zidovudine were again discussed with you, and at present
15 the feeling was that you should merely continue to
16 monitor [REDACTED] and not instigate therapy yet:

17 "This decision is difficult as there is a body of
18 opinion who feel that Zidovudine therapy should be
19 started when the CD4 numbers fall below 500 c/mm. However,
20 at present this is not the policy of Ruchill Hospital,
21 who, although starting Zidovudine therapy earlier than
22 would have been their previous habit, are still
23 concerned about resistant strains."

24 So it was obviously quite a difficult decision in
25 relation to the treatment?

1 A. As far as treatment was concerned, they were giving us
2 their opinion that if he started on it, he would have to
3 continue and if he came off it, then there could be
4 a jump in his condition with being HIV. So it was
5 decided to leave it until it had to be used.

6 Q. Right. And so why were you told that if he started it,
7 he had to carry it on?

8 A. Because it was a case that it might load his immune
9 system more.

10 Q. Was there any concern about what might happen if he
11 started the drug and then stopped it in relation to
12 resistance of the virus?

13 A. Yes, they thought that it might lower his resistance to
14 the virus. If he started it, he would have to continue
15 with it.

16 Q. Because if he stopped it that might make the virus
17 resistant to it and it couldn't be used again?

18 A. Yes.

19 Q. Was that your understanding?

20 A. Yes.

21 Q. Did you feel that you were able to fully discuss this
22 with his consultants and be involved in the
23 decision-making process?

24 A. It was really [REDACTED]'s decision but we supported
25 him and when he was saying that he didn't want to start

1 it then and they said it wasn't absolutely imperative to
2 start it, then we backed him.

3 Q. Right. So there were discussions with all of you about
4 the pros and cons?

5 A. Yes.

6 Q. And it was [REDACTED]'s decision at the end of the day?

7 A. Yes.

8 Q. If we move on to WIT0040084, I think this
9 is February 1991, when [REDACTED] will have been 15.
10 Is that right?

11 A. Yes.

12 Q. I think this is the time when treatment is started with
13 Zidovudine. It says, about the fourth line down:
14 He has reminded in general good health. Clinically
15 he is well, attending school normally and participating
16 in all his usual activities. No symptoms suggestive of
17 progression of his HIV infection but unfortunately his
18 CD4 counts have fallen to between 200 to 300 units per
19 cubic millimetre. We are now recommending that
20 Zidovudine therapy be started earlier than was our
21 previous practice and we discussed the pros and cons at
22 length with [obviously you] and have started him on
23 treatment.

24 Did you feel there was some uncertainty on the part
25 of the doctors about treatment and when would be a good

1 time to start?

2 A. I think there was. I think there was some uncertainty.
3 I think the fact that they were saying that his immune
4 system could drop more if he came off it, that to put
5 him on it too early would have been the wrong thing to
6 do, but then they weren't sure if putting him on it
7 earlier might have prevented something else occurring.

8 Q. Yes. I mean, obviously, it was a new virus, so they
9 were looking at new treatments, so it was an uncertain
10 time for the doctors as well as patients.

11 It mentions that he had to take the Zidovudine five
12 times a day.

13 A. Yes.

14 Q. What form was that medication in?

15 A. Tablet form.

16 Q. Tablet form. Was it the case that it had to be taken at
17 regular intervals over 24 hours?

18 A. Yes.

19 Q. Yes. So did he have to take it to school with him?

20 A. It was planned that he only had to take one with him to
21 school.

22 Q. Right. Was it stressed to him the importance of taking
23 the doses at the right times?

24 A. Not particularly.

25 Q. Not particularly, no. Do you think [REDACTED] found it

1 difficult taking his medication at school?

2 A. No.

3 Q. No?

4 A. He was all right with it.

5 Q. We see also that he is given an additional medication

6 against pneumocystis and he is on nebulised Pentamidine.

7 Was [REDACTED] given any support in respect of taking

8 his medication and the fact that it was important that

9 he continue taking it?

10 A. He was informed by the hospital and he was encouraged by

11 us.

12 Q. Right. Did he need reminding to take it?

13 A. On the odd occasion, yes.

14 Q. I think if we move on to September 1991, WIT040086.

15 This is Dr Gibson to [REDACTED]'s GP, mentioning that

16 he has had a recent upper respiratory tract infection

17 but still no symptoms suggestive of progression of his

18 HIV infection. It is noted that he does have some

19 lesion and patches in his mouth. Did he have problems

20 with skin changes in his mouth or --

21 A. We just put it down to his -- we felt he had tonsillitis

22 because of his haemophilia. They wouldn't do anything

23 about it and this was just an infection coming from

24 there.

25 Q. Right:

1 It was thought that these were more viral and
2 his CD4 cell count was remaining stable at that time and
3 he was taking his medication.

4 In December 1991, which is WIT0040087, there is
5 mention of a previous sore throat which has now
6 resolved:

7 But [REDACTED] has lost a bit of weight at this
8 time.

9 As you will see half way down paragraph 1:

10 "His appetite has been less good of late and his weight
11 has fallen by two and a half kilos." He continues on his
12 medication. His CD4 count is still down and it's noted by Dr
13 Gibson that this, combined with his loss of weight,
14 "is a rather concerning feature."

15 She is worrying about the impacts of the drugs in
16 relation to marrow toxicity and wondering about reducing
17 his Dapsone. Was that to prevent lung problems?

18 A. It was to prevent the build-up of fluid.

19 Q. Yes. She notes at the bottom:

20 He "is now almost 17 years old and would most
21 appropriately be looked after in an Adult Unit."

22 So she is writing to Dr Lowe and he is moving into
23 Dr Lowe's care at that point. If we look at
24 WIT0040088, this is Dr Gibson's referral letter to
25 Dr Lowe. It notes in the second paragraph:

1 "He has very little in the way of problematic
2 bleeding episodes and we almost never see him because of
3 his haemophilia per se."

4 She notes in the third paragraph:

5 "Although his general health is reasonably good, we
6 are probably beginning to see the progression of HIV
7 infection."

8 She mentions the symptoms that we have been looking
9 at. She also refers to ulcers and the fall in the CD4
10 cell count. If you go over the page to page 2, she
11 talks about liver blood test results and she notes
12 there:

13 "He is positive for antibody to Hepatitis C." You
14 didn't know, even until [REDACTED] died, that he had
15 Hepatitis C?

16 A. Not until after he died. We were never told.

17 Q. She says:

18 "I would be very grateful if you would take over his care
19 as he is now almost 17. He is a delightful young man
20 and I will be anxious to hear how he progresses."

21 I think if we look at WIT0040128, we will see the
22 blood test which showed that [REDACTED] was positive
23 for the antibody to the Hepatitis C virus. You will see
24 that the date's in the bottom left-hand corner. That's
25 dated 15 June 1990 and the date of the specimen was

1 4 June 1990. Were you ever told that [REDACTED] was
2 being tested for the Hepatitis C virus?

3 A. No.

4 Q. Do you think [REDACTED] knew that he had Hepatitis C?

5 A. No, because he would have told us.

6 Q. Can we move on to WIT0040090? This is the letter back
7 from Professor Lowe, after Dr Gibson referred
8 [REDACTED] there. It tells us that at this stage
9 [REDACTED] is nearly 17:

10 "a very pleasant young man who is in his 6th year
11 at school and is about to sit his preliminary examinations
12 followed by English and Accountancy Highers in May,
13 he has History already. He is applying for a college and
14 hopes to do an HNC in computing."

15 How did [REDACTED] get on in all his exams at
16 school?

17 A. He passed them.

18 Q. He passed them?

19 A. Hm-mm.

20 Q. Which can't have been easy given that he had numerous
21 hospital visits?

22 A. No, he did want to do an HNC in computing.

23 Q. He went on to do that?

24 A. Yes.

25 Q. That took a year, did it?

1 A. Yes.

2 Q. So he got the exam results he needed for what he wanted
3 to do after he left school?

4 A. Yes.

5 Q. Further down it says, second paragraph:

6 "There were no particular symptoms of HIV infection."
7 Then if we go over the page to 0091, there is
8 mention of a small boil on his chin from shaving. His
9 ear is being obscured with wax and they are awaiting
10 blood test results. He was also seen at that
11 appointment by a DrMcMenamin from Ruchill, and I think
12 at that appointment you met unit staff. Was that the
13 staff at Glasgow Royal Infirmary?

14 A. Yes.

15 Q. That included nursing staff, physiotherapy and a medical
16 social worker. Then:

17 "I will discuss with Dr Lowe how he wishes to
18 continue his liaison with the children who are currently
19 being transferred here from Yorkhill."

20 There is a handwritten note that:
21 "We'll continue with the 'monthly clinic'."
22 So basically at this time [REDACTED]'s care is
23 being passed over to Dr Lowe?

24 A. Yes.

25 Q. To Glasgow Royal Infirmary. Would he usually see

1 somebody from Ruchill at these clinic appointments?

2 A. Once he went to the Royal, anything that was done was in
3 conjunction with Ruchill.

4 Q. Right. Okay. He is continuing with the same
5 medications. If we move on to June 1992, WIT0040092,
6 I think [REDACTED] had problems with his eyes. Do you
7 remember that?

8 A. It was just soreness he had but he did get glasses for
9 them.

10 Q. Did he? Well, this is a letter from a doctor to an
11 ophthalmology doctor, asking him to see [REDACTED]
12 because he is complaining of a two to three week history
13 of photophobia affecting his right eye. He is referring
14 him to this specific doctor, because he understands that
15 he has a special interest in ocular disease in the
16 immuno-compromised:

17 "I would be grateful if you could arrange to see him
18 and check we are not missing any underlying pathology."

19 So I think [REDACTED] did see Professor Kirkness.
20 If we look at WIT0040094, this is his response, saying
21 that he could find no external ocular disease and really
22 no abnormality. He says:

23 "I did not think his symptoms sounded migrainous, but
24 they might just have been stress related. In any rate
25 I have not arranged to see him again but will be very

1 happy to do so should he develop any further symptoms."

2 A. We actually put it down to the fact of his eyes being

3 sore because he spent so long on the computer.

4 Q. Did you?

5 A. Yes.

6 Q. A common feature of boys that age?

7 A. I think so.

8 Q. So you didn't think it was to do with stress?

9 A. No.

10 Q. Okay. I think around this time [REDACTED] started to

11 have more respiratory tract infections. If we look at

12 WIT0040095, he has been on holiday in Spain. Were you

13 with him there?

14 A. Yes.

15 Q. So it was a family holiday?

16 A. Yes.

17 Q. He was obviously bothered by a cough during the holiday?

18 A. Yes.

19 Q. And was feeling slightly breathless. He had some

20 diarrhoea in Spain but this had settled and also a nose

21 bleed, which caused him to cough up some blood. He had

22 some seborrhoeic dermatitis of his face, which was like

23 a rash on his face?

24 A. We actually -- we took him to a herbal doctor, a Chinese

25 herbal doctor in Glasgow and it was his reaction to the

1 ingredients of a McDonalds, because he used to eat a lot
2 of McDonalds food and this was the reaction. So once he
3 stopped taking them, the rash on his face went away.

4 Q. So you think the rash was linked to too many McDonalds?

5 A. Yes.

6 Q. Right. It's noted at the bottom of this letter:

7 "I think this man has a mild upper respiratory tract
8 infection, although given the nature of the underlying
9 illness, this should be taken seriously."

10 So a chest x-ray was arranged and sputum sent for
11 culture and he is given an antibiotic prescription, and
12 is to return to the clinic for review in one week's
13 time. The review letter is WIT0040096, saying that
14 the chest x-ray showed no focal abnormality. There is
15 a heavy growth of haemophilusinfluenzae, which is
16 sensitive to amoxycillin. He is obviously feeling
17 slightly better but still with a troublesome cough and
18 he continues on his medication. Did things improve
19 after that for a while?

20 A. Yes, they did for a while.

21 Q. Can we move on to October 1992 at WIT0040098. Once
22 again [REDACTED] is having problems with a cough which
23 is bloodstained on one occasion, and he has a fungal
24 infection of his thumbnails and facial folliculitis.
25 I think that's when the hair follicles become a bit

1 swollen and red. He has received another course of
2 antibiotics. His haemophilusinfluenzae has grown again
3 from the sample, and once again I think the antibiotics
4 have helped and he is referred to the dermatologist in
5 respect of his skin and nail infections.

6 What were these skin and nail infections like?

7 A. His nails -- it was like a rot; as if his nails were
8 rotting. They were thinking it was possibly a side
9 effect of the medication he was taking.

10 Q. Right. Then he is referred to a dermatologist and the
11 reply in that respect is 16 October 1992, which is
12 WIT0040099. This talks about [REDACTED] having
13 developed a rash on his scrotum and in June on his face.
14 He is a student at this point. So this is presumably
15 while he is doing his computing course. This
16 dermatologist, John Thompson, thought that he had gross
17 fungal infections of all of his toenails and two of his
18 fingernails, and that the rash on his groin is that of
19 a fungal infection, as is that on his face.

20 He suggests a drug that may be used and he also
21 suggests that [REDACTED]'s liver function tests are
22 checked. Do you remember if that helped, the treatment
23 he was given then?

24 A. I don't think it did help. I can't really remember.

25 Q. Then in October 1992 [REDACTED] was admitted to

1 hospital with pneumonia. Was this just after he left
2 school and while --

3 A. Well, they never told it was pneumonia. They just told
4 it was a chest infection, if anything.

5 Q. The letter is WIT0040100. You will see the diagnosis,
6 lower left, lobe pneumonia, and it seems that he was
7 admitted directly to the ward following review by
8 Dr Lowe. Then increasingly he has a severe cough
9 productive of green sputum but no coughing of blood; he
10 is breathless with lethargy and malaise and occasional
11 vomiting after coughing. That seemed to be something
12 that started to happen as well?

13 A. Yes.

14 Q. So it says:

15 "he was referred over to us for a short inpatient
16 stay."

17 Do you remember how long it was?

18 A. I think a few days. I can't remember. I think it
19 probably was only a few days.

20 Q. It was thought that the most likely pathogen was
21 a bacterial one and he was commenced on Augmentin and he
22 was discharged to be followed up in the haemophilia
23 outpatient clinic. I think he then had a further
24 admission for five days in November 1992, if you look at
25 WIT0040102. This is dated 25 November 1992. The

1 diagnosis is written at the top: "haemophilusinfluenzae
2 chest infection" and Haemophilia A. We see he was
3 admitted on 12 November until 17 November, having been
4 unwell at home for about one or two weeks. Then an
5 increasing problem with breathlessness and a productive
6 cough. He made a rapid response to treatment and was
7 then allowed home.

8 So I think [REDACTED] continued to have problems
9 with chest infections?

10 A. Yes, once he started, they just kept going.

11 Q. They kept coming and I think he was still at school at
12 this time, was he?

13 A. 1992? No.

14 Q. 1992. I just want to check your statement. Yes, he
15 finished school, you say, in 1993, aged 18 years. So he
16 was obviously having to have spells off school.

17 In March 1993 I think [REDACTED] started a new drug
18 in respect of his HIV, DDC. If we turn to WIT0040104.
19 This notes, as you have said, that [REDACTED] is still
20 chesty. I think otitis media is inflammation of his
21 middle ear. That has improved. He has now started the
22 new antiretroviral drug, DDC, released on compassionate
23 basis for him. This is to be taken with the zidovudine
24 as well as his prophylaxis treatment for PCP. Were you
25 involved in any discussions in relation to [REDACTED]

1 starting this new medication?

2 A. No.

3 Q. Okay. And it highlights there the side effects, the
4 most important one being pancreatitis.

5 I think that same month [REDACTED] was admitted to
6 hospital again on two separate occasions. So it seems
7 like he missed a lot of schooling in his last school
8 year. WIT0040105. I think it became apparent during
9 these admissions that in fact [REDACTED] hadn't been
10 taking his medication?

11 A. Yes.

12 Q. Is that right? You touch on the difficulties in
13 relation to that for you as a parent, because you didn't
14 feel you could nag him all the time about it and he was
15 being treated as an adult by the hospital. So you let
16 him have control of his own medication, so to speak?

17 A. Yes.

18 Q. So did you know that he had stopped taking his
19 medication?

20 A. No.

21 Q. No. If we look at paragraph 22 of your statement,
22 WIT040037. You say there what you have told us
23 already, that it was emphasised to him about the
24 significance of taking the medication and he was told
25 that once he started taking them, he would have to keep

1 taking them or his HIV symptoms would come back with
2 a vengeance, but despite this advice, he just stopped
3 taking them. You say you didn't think the previous
4 chest infections were directly linked to HIV and you
5 think that he stopped taking the tablets because he was
6 fed up taking them and the way they made him feel. You
7 say:

8 "The side effects made him sick and tired."

9 How did that effect him, those side effects?

10 A. I think the side effects were quite straining on him.

11 He was trying to work -- he was trying to work, trying
12 to just be normal and he felt the side effects were just
13 bringing him down.

14 Q. Did he have any other side effects, other than feeling
15 sick and tired?

16 A. No, just his chest infections that kept coming back.

17 Q. You say you think he got to a point where he just
18 decided to let nature take its course. He was young.
19 He didn't tell you, as you have said, that he had
20 stopped taking the tablets and you kept asking him if he
21 was taking them and he said "yes", but he had obviously
22 stopped by that stage. He didn't tell you because:

23 "he didn't want to bother us. He could see how
24 much stress we were under. We think he came off his
25 medication several times but we weren't privy to that

1 information because he never told us and the hospital
2 wouldn't tell us."

3 Do you think the hospital realised before you did
4 that he had stopped taking his medication?

5 A. I don't know.

6 Q. You say that:

7 "Other than going into his room and counting his
8 tablets, there was nothing that we could do about it."

9 You feel that the fear of the stigma and the stress
10 on your son of the secrecy in relation to his diagnosis
11 put so much pressure on the him that he stopped taking
12 his medication. As you have said to us before, he
13 didn't tell anybody at all he had the virus. Over the
14 page at 0038 you say:

15 "He was fed up. I do not think he thought it through
16 properly when he came off the medication. We could not
17 keep track because when he became an adult patient we
18 lost control of managing his care. The hospital would not
19 tell us anything. We could not search his room and count the
20 tablets. He had made up his mind. He was very fit and
21 went to the gym. Maybe he thought he would survive
22 without medication. Perhaps he thought that he was
23 indestructible."

24 Q. So going to the admissions in March 1993, WIT040105, this
25 is really a discharge summary of the two admissions, which

1 highlight the chest infections and the fact that he may now
2 have bronchiectasis.

3 PROFESSOR JAMES: Bronchiectasis.

4 MS PATRICK: Thank you. Which I think is a more severe
5 condition which causes widening of the airways and his
6 symptoms really are much coughing, coughing up of blood, and
7 he had to undergo a bronchoscopy, which is mentioned at the
8 bottom of this page 1, and he has been given IV antibiotics.

9 If we go over the page, he was given further
10 antibiotics and then discharged home on 2 April -- this
11 is about half way down -- to continue with his
12 medication with septrin, which they are hoping will
13 reduce the number of bacterial chest infections he is
14 having.

15 At the bottom it says it was explained to
16 [REDACTED] -- and also subsequently, I think, to you --
17 that his coughing up of blood is probably due to eroded
18 blood vessels in association with the bronchiectasis,
19 and the policy would be to continue with appropriate
20 antibiotics and treat any exacerbations of chest
21 infections in this way. The plan is to continue to
22 regularly review him and it's noted there that
23 Professor Lowe discussed with you [REDACTED]'s general
24 condition and you appreciated at that time that he now
25 had a very low CD4 count, with major risk of further

1 opportunistic infections including chest infections. It
2 is noted there he had apparently not been taking his
3 antiviral medication regularly and you were now giving
4 him this regularly to help compliance. So do you
5 remember that discussion?

6 A. Yes, yes, I do.

7 Q. Yes. What was Professor Lowe saying to you then?

8 A. How important it was that [REDACTED] keep on his
9 medication and how he appreciated that his being an
10 adult, that we weren't always able to enforce it but to
11 just try and be more forceful of it.

12 Q. In April 1993 -- that's just after that -- WIT0040108,
13 I think [REDACTED] continued to suffer nausea and
14 Professor Lowe was wondering if it might be linked to
15 his zidovudine and he was given extra medication for his
16 nausea in the meantime. I think after that [REDACTED]
17 continued to attend for review appointments. Were you
18 going to these with him?

19 A. He was going on his own.

20 Q. He was going on his own, okay. I think his coughing up
21 of blood cleared up but he continued to have a cough.
22 In June 1993, WIT040111, it's noted that he has no new
23 problems to report. His chest symptoms have now settled
24 and he has no occurrence of coughing up blood.

25 Third paragraph. He is given treatment for the

1 fungal infection of his nails, which we spoke about
2 earlier. I think this must have been around the time
3 that [REDACTED] was leaving school. Was he able to go
4 away in the summer he left school?

5 A. He went away to Germany with some of his Scouting
6 friends but I don't know if it was that year.

7 We were just discussing that he actually went to
8 summer camp with all the boys from Yorkhill but that was
9 much earlier. He went to Germany with the Scouting
10 group for a week and was taken unwell there as well.

11 Q. Yes. I was about to go on to that. You mention there
12 a summer camp with the other boys from Yorkhill?

13 A. It was organised through the Round Table, I think, it
14 was organised. And it was in Yorkhill it was organised,
15 while he was there and it was him and the other
16 haemophiliac boys. They all went to the Hole in the
17 Wall Gang Camp in America and then they had a couple of
18 days in New York as well. But it was hospital staff
19 that were with them when they went on that, but when he
20 went on the Scout trip it was just him and his friends.

21 Q. Did you say it was organised by Round Table?

22 A. I think it was Round Table.

23 Q. What is Round Table?

24 A. That was local charity in Glasgow. Some of the funds
25 came from the Macfarlane Trust and the Round Table is an

1 association and they helped with the boys as well, you
2 know, accommodation.

3 Q. So you funded the trip?

4 A. I think it was the Macfarlane Trust that funded the
5 trip. We paid -- I think it was a joint venture between
6 the Macfarlane Trust. We also paid the donation and
7 I think Glasgow as well.

8 Q. With regard to the Macfarlane Trust, I think it's
9 mentioned in your statement that the Yorkhill staff
10 encouraged you to make yourself known to the
11 Macfarlane Trust. Is that right?

12 A. Yes.

13 Q. And that's a trust which gives assistance to people with
14 haemophilia who are infected with HIV and their
15 families?

16 A. Yes.

17 Q. And you mention in paragraph 29, which I don't think we
18 need to go to, that they offered you counselling, the
19 trust?

20 A. Yes.

21 Q. Did you take that up?

22 A. No.

23 Q. No. Why not?

24 A. I think we were just too sore. We didn't want to bring
25 it all back again.

1 Q. Right.

2 A. That was about five or six years after [REDACTED] died
3 that they offered us counselling.

4 Q. So did they offer you counselling before that?

5 A. I can't remember. I don't think so, but I can't
6 remember, to be honest.

7 Q. Well, if we look at WIT0040112, this deals with
8 [REDACTED]. It tells us about [REDACTED] on his
9 return from his holiday in Germany. Dr Kennedy notes
10 that he:

11 " ... did not like the look of [REDACTED] today;
12 he has marked facial dermatitis on the right side."
13 He looked tired and pale and he had lost a great
14 deal of weight:

15 "He was reluctant to admit his weight loss but
16 attributed it to a holiday in Germany, when he ate very
17 little."
18 He doubts that that can be the only reason. He is
19 noting that [REDACTED] is continuing to have chest
20 problems and a lesion, I think, on his tongue. He is
21 prescribed more medication, Erythromycin, and asked to
22 come back so that his weight can be reviewed and in the
23 meantime he should continue on the same drug treatment.

24 So it is around about this time that [REDACTED] is
25 starting his computing course?

1 A. Yes.

2 Q. And where did he do that?

3 A. ██████████ College in ██████████.

4 Q. And then I think things improved for ██████████. If we

5 look at WIT0040114, we see that ██████████ is keeping

6 well. He also had a job, did he, at the same time as

7 being at college?

8 A. Yes.

9 Q. What was that?

10 A. It was delivering Chinese meals, believe it or not.

11 Q. Was it?

12 A. Yes.

13 Q. Good. How did he find being at college and working in

14 the evening?

15 A. He thoroughly enjoyed it but it was taking its toll on

16 him because he used to get quite tired.

17 Q. But he is gaining weight at that point, still with chest

18 problems, and continuing on the same medication, and he

19 was going to go to Spain for Christmas?

20 A. Yes.

21 Q. Was that with you?

22 A. Yes, it was the last family holiday we had together.

23 Q. And how was ██████████ during that holiday?

24 A. He seemed to be fine apart from the cough. I think he

25 had a nose bleed while we were away. I think he had

1 a touch of diarrhoea as well but we put it down to
2 drinking water -- you know, tap water that he shouldn't
3 have been drinking, just a change in diet. But he had
4 a good time that fortnight we were away.

5 Q. I think he developed mouth ulcers again over Christmas
6 and was given more treatment for that. Do you remember
7 that?

8 A. No.

9 Q. The reference for that is WIT0040116 but I don't think
10 we need to look at that. In May 1994 [REDACTED] had
11 an admission to hospital for about a month due to
12 gastrointestinal bleeding. Is that right? The document
13 relevant to that is WIT0040117. This shows that
14 [REDACTED] was admitted to hospital on 24 May 1994 and
15 was discharged on 22 June 1994 with a history of
16 vomiting, general weakness, lack of energy and fever.
17 He still has the intermittent cough. The chest x-ray
18 was normal. He underwent a colonoscopy, which
19 unfortunately did not produce much information, as his
20 bowel was poorly prepared. He was given iron and
21 a course of amoxycillin. So presumably this was time
22 that [REDACTED] missed from his course?

23 A. Sorry?

24 Q. Presumably this was time that [REDACTED] missed from
25 his --

1 A. No, that was during the summer break.

2 Q. Right. So it had finished by then. Could we return to
3 your statement at paragraph 21, which is WIT0040037?
4 I think you tell us in the second sentence of
5 paragraph 21 that after he left college [REDACTED]
6 started working full-time for a family-run catering
7 business in their office?

8 A. Yes.

9 Q. And he obviously enjoyed his work because he tried to go
10 there no matter how ill he felt. And you say:
11 "Come hell or high water, he would go to his work."
12 And you tell us there that he was keen to take on
13 another job with Makro?

14 A. Yes.

15 Q. But you didn't allow him to start that and took his
16 uniform back.

17 A. That sounds pretty hard. We talked it through --
18 I know, the way it's put down there, it sounds as if we
19 have dictated to him.

20 Q. No, I don't think anybody would --

21 A. -- but what we actually done was we talked it through
22 him and gave him the pros and cons of how tired he was
23 working one job and how tired he would be working two of
24 them. So he fully agreed with us and that's why. And
25 I did take his uniform back to them. But he eventually

1 lost his job in the catering office because it was
2 a family-run business and -- my husband actually had
3 more to do with him than what I did, and at times he was
4 going to work when he shouldn't have been there and they
5 had to phone my husband to come and collect him or he
6 would have to go in and say he would have to go to the
7 hospital.

8 They were very supportive and very upset that they
9 had to let him go but there was nothing else they could
10 do.

11 Q. Did his employers know that he had HIV?

12 A. No, they knew he was haemophiliac but they didn't know
13 his HIV status either.

14 Q. You told us earlier how you tried to let [REDACTED]
15 live as normal a life as possible but it must have been
16 very difficult for you in relation to something like
17 this to let him do that, at the same time trying to care
18 for him.

19 A. Well, we had to let him live his life. We didn't know
20 how long it was going to last. We knew it would
21 eventually -- we weren't sure, we didn't know, so he had
22 to make his own decisions. And he did appreciate our
23 comments, when we felt that we had to intervene, that we
24 weren't nagging, that it was just constructive.

25 Q. Yes. So he managed that job for three months, you said?

1 A. Yes.

2 Q. And then he became too unwell to continue with it?

3 A. Yes.

4 Q. It appears from the medical records that [REDACTED]

5 stopped taking his medication again in the summer of

6 1994.

7 A. Yes.

8 Q. Is that right? Do you know why he did this?

9 A. I think just, as we said earlier, he just got fed up

10 with having to take tablets all the time and how ill

11 they were making him feel.

12 Q. So by this time he managed three months of work and then

13 was not working and his condition was deteriorating?

14 A. Yes.

15 Q. And you tell us in paragraph 23 of your statement,

16 WIT0040038, that in January 1995 he was admitted to

17 Ruchill Hospital. Can you remember what his symptoms

18 were then?

19 A. He was being sick but, when he was admitted to Ruchill,

20 he went in with knee bleeds. All it was was he had

21 a bleed in his elbow, I think, and he was being quite

22 sick.

23 Q. Right. You say in your statement that the doctors did

24 not know what was wrong with him, so they investigated

25 with a gastroscop and discovered that he had an ulcer

1 on his lung --

2 A. Yes.

3 Q. -- which could be treated, and you say that a few hours

4 after the gastroscope had been used, he was paralysed.

5 A. Yes.

6 Q. And that no one knew what caused this.

7 A. No.

8 Q. And you say his lungs were badly damaged and he could

9 not grip, mobilise, feed himself or go to the toilet.

10 A. The only movement he had was his head. He couldn't move

11 anything else.

12 Q. And what did the doctors say to you about this?

13 A. They said they didn't know what had caused it.

14 Q. And so what did the hospital suggest?

15 A. Well, at that point they diagnosed him that he didn't

16 have long to live. So they never suggested anything.

17 Q. And so it was at that point, on 13 February 1995, that

18 you took him home?

19 A. Yes.

20 Q. And you started, you and your husband, to care for him

21 there yourselves?

22 A. Yes.

23 Q. And you had a bedroom made up for him downstairs and

24 nurses overnight came in to help you look after

25 ██████████.

1 A. We initially tried to do it on our own but it wasn't
2 possible. So Ruchill organised nurses to come in
3 overnight so at least we could go to sleep.

4 Q. How was [REDACTED] being fed at that point?

5 A. He was eating normally.

6 Q. He was eating fine?

7 A. Hm-mm. He wasn't eating a lot but he was eating. We
8 had to feed him because he couldn't feed himself.

9 Q. Right.

10 A. And we told him that nurses were coming in overnight.
11 The only thing he asked us to do is that if he needed
12 the toilet, he wanted his Dad or I to take him.

13 Q. So that was how he was toileted? One of you had to
14 carry him?

15 A. Well, he had a commode. We had to lift him on to the
16 commode but it took two people to lift him so as not to
17 hurt him, because he was sore.

18 Q. Do you feel you got the support that you needed at that
19 time?

20 A. Yes, we did.

21 Q. You did?

22 Then, moving on to paragraph 24, in February 1995,
23 just before [REDACTED]'s 20th birthday, he started
24 having nose bleeds and you phoned
25 Glasgow Royal Infirmary about these and I think after

1 three days somebody came to the house to see him?

2 A. Yes.

3 Q. And they cauterised the bleed but by then [REDACTED]

4 had blood in his lungs and he developed a lung

5 infection. He needed oxygen and you were able to give

6 him that at home, were you? And then he sadly died on

7 7 March 1995, holding your hands. He said:

8 "Dad, just leave me. I'm okay."

9 And he died telling you both that he loved you.

10 His death must be a very great loss to you. You

11 must be very proud of how brave he was throughout this?

12 A. Yes, we are. (Pause)

13 Q. Are you all right to continue?

14 A. Yes.

15 Q. Thank you.

16 THE CHAIRMAN: Ms Patrick, have you got much more to do?

17 There is quite a bit in the statement.

18 MS PATRICK: Yes.

19 THE CHAIRMAN: I think, Christine, we will have a break at

20 that stage. I think it might be an appropriate moment

21 to break.

22 (12.57 pm)

23 (The short adjournment)

24 (2.00 pm)

25 THE CHAIRMAN: Yes, Ms Patrick?

1 MS PATRICK: I'm wondering if I could please refer you to
2 paragraph 31 of your statement, which is on page
3 WIT0040041. This is about the financial position in
4 respect of your diagnosis, and I think you are
5 suggesting that [REDACTED]'s infection with HIV may
6 have had a knock-on effect on your application for life
7 assurance.

8 A. Yes.

9 Q. So you say in paragraph 31 that you have life assurance
10 and a pension and that you had both in place prior to
11 your diagnosis of Hepatitis C in 1991. You say that
12 when you tried to top up your life insurance policy --
13 and I think this must have been after you developed
14 jaundice but before you found out you had Hepatitis C?

15 A. Yes.

16 Q. Your GP declined to sign the application form. What did
17 he say to you, when he declined to sign it?

18 A. He later suggested to us that he thought I might have
19 had HIV after my jaundice.

20 Q. Right.

21 A. It was tested but it came back negative. But he felt
22 that it was going to be so difficult to try and top it
23 up without all different loopholes to try and jump
24 through. He thought it was easier not to sign it at
25 all.

1 Q. Right. So your GP thought that your jaundice might have
2 been a sign that you had --

3 A. HIV.

4 Q. -- HIV, okay. So he refused to sign the form that you
5 needed to be signed in order to top up your life
6 assurance?

7 A. Yes. He was also worried about cross-infection because
8 I was doing home therapy. There may be
9 a cross-infection as well with HIV.

10 Q. So he obviously knew that [REDACTED] had HIV at that
11 time?

12 A. I suspect he must have done.

13 Q. He must have done. You are saying there that he knew
14 that you were treating [REDACTED] yourself?

15 A. Yes.

16 Q. You say there the insurance industry denied you life
17 insurance even though your son's HIV was nothing to do
18 with you. Did you manage to make any application?

19 A. We did make an application. It was eventually cleared
20 up. We were able to top up through Norwich Union but
21 everything had to come back. It was such a long,
22 drawn-out affair even though [REDACTED] and I weren't infected
23 with HIV, because it was obviously apparent there was an
24 infection of some sort in the house, that we had to wait
25 for tests to be --

1 Q. Can you remember if the form had to specify that
2 [REDACTED] had HIV or not?
3 A. I can't remember.
4 Q. You can't remember?
5 A. I can't remember.
6 Q. But it was a long, drawn-out process?
7 A. Yes.
8 Q. Do you know if you had to pay more than you thought you
9 would because of --
10 A. I'm not sure. I can't remember.
11 Q. You are not sure, okay.
12 A. No, we don't remember if we had to pay more.
13 Q. Okay, thank you. So you say you now have minimal life
14 insurance but you did manage to top it up eventually?
15 A. Yes.
16 Q. You have no personal health insurance and you tell us
17 there that you received a payment of £20,000 from the
18 Skipton Fund in late 1990?
19 A. Yes.
20 Q. In paragraph 32 you tell us that [REDACTED] received
21 two ex gratia payments from the Macfarlane Trust?
22 A. Yes.
23 Q. You go into more detail about that in the paragraph
24 below that, paragraph 33. You say that he received the
25 first payment of £20,000 in 1990, when he was 15 years

1 old and the second payment in 1991. You say that in
2 order to receive the payments, he had to sign a waiver
3 saying that he would not take any further legal action
4 against the government in respect of contracting HIV?

5 A. That's right.

6 Q. Was that a waiver that was given to him by the
7 Macfarlane Trust?

8 A. It was a lawyer insisted that he signed a waiver or the
9 money wouldn't be released to him.

10 Q. Was this the lawyer who helped [REDACTED] apply to the
11 Macfarlane Trust?

12 A. Yes.

13 Q. Okay. You say he was 14 or 15 at the time he signed the
14 waiver and he went himself to see the solicitor and you
15 didn't go with him?

16 A. We were with him but we weren't in the room with him.

17 Q. Right. You say you weren't allowed to go in to see the
18 solicitor with him?

19 A. No.

20 Q. Why was that?

21 A. It was because he was to go in by himself. We could be
22 with him but not when he actually signed the document.

23 Q. Okay. You go on to say that you used the money to buy
24 a car for [REDACTED] and you put the rest of the money
25 aside for him?

1 A. Yes.

2 Q. That was obviously the car that allowed him to work
3 evenings?

4 A. Yes.

5 Q. While he was at college?

6 A. Yes.

7 Q. Yes. You say if he wanted something, he used the money
8 to buy it for him and he used the money to go to Germany
9 with friends. He didn't want the money for himself, he
10 wanted you to use it, and you thought of it as blood
11 money and you received an allowance also from the
12 Macfarlane Trust for his funeral. Is that right?

13 A. Yes.

14 Q. Going back to paragraph 32, on the page before, 0041,
15 did you also receive some allowance from the
16 Macfarlane Trust while [REDACTED] was still alive?

17 A. Yes, we did.

18 Q. What were these payments?

19 A. I can't remember how much they were. I can't remember.
20 It was -- I can't remember how much we received from
21 the Macfarlane Trust.

22 Q. Was it a monthly payment?

23 A. Yes, it was.

24 Q. These stopped when [REDACTED] died?

25 A. Yes, they did.

1 Q. Then you mention that your grandson, who we will come on
2 to shortly, receives at the moment £250 per month?

3 A. Yes.

4 Q. This is from the Macfarlane Trust as well?

5 A. Yes.

6 Q. This will last as long as he is at school?

7 A. In full-time education.

8 Q. Okay. Could you give me a minute, please? (Pause)

9 I wonder if I could go back a point we were talking
10 about earlier, which was about how you came to know,
11 which I think you did -- you can correct me if I am
12 wrong on this -- that [REDACTED] had got the HIV virus
13 from Factor VIII. I think you told us that at that time
14 you were told of [REDACTED]'s diagnosis, that
15 connection wasn't made and you weren't told that it was
16 caused by the Factor VIII?

17 A. No.

18 Q. No. I think by the time you told [REDACTED] in 1989
19 that he had contracted HIV, you were able to tell him
20 that he had contracted HIV from infected Factor VIII,
21 which is in paragraph 15 of your statement. Is that
22 right?

23 A. Yes.

24 Q. I just wondered how you had come to know that by that
25 time?

1 A. Well, it was through the hospital. They told us it was
2 through infected Factor VIII but they couldn't tell you
3 which batch number it was.

4 Q. Right. So some time between the time that you found out
5 [REDACTED] had HIV and the time you told him yourselves
6 in 1989, somebody at the hospital --

7 A. Yes.

8 Q. -- told you, and I take it that position coincided with
9 the other families you knew there too?

10 A. Yes.

11 Q. Are you able to say when that might have been?

12 A. I can't remember. My husband seems to think it was
13 round about the time when heat treatment started, that
14 they discovered -- just before heat treatment they
15 discovered that it might be that but then they
16 discovered that heat treatment didn't make any
17 difference either.

18 Q. Right. Okay, thank you.

19 You mention in paragraph 24 of your witness
20 statement, which is at WIT0040038, about the
21 possibility of a post mortem after [REDACTED] died and
22 I think the possibility of this was discussed with you
23 a couple of days after his death. Is that right?

24 A. Yes.

25 Q. How did you feel about that?

1 A. [REDACTED] always said if it would help someone, then
2 it was the right thing to do. We were very much of the
3 same opinion. There was another child that was showing
4 the same symptoms at that time and we felt if it could
5 help them.

6 Q. Was that another child with haemophilia?

7 A. Yes.

8 Q. With HIV?

9 A. Yes.

10 Q. So you felt that if a post mortem was carried out on
11 [REDACTED], it may assist this child?

12 A. Yes.

13 Q. So you agreed to that --

14 A. Yes, we did.

15 Q. -- being carried out. You say that you went to
16 Ruchill Hospital about six months later for the post
17 mortem results only to find that the record of the post
18 mortem had been mislaid?

19 A. Yes. We have actually been back at least twice since
20 then and still haven't had anything from anyone to tell
21 us what happened.

22 Q. Were you given any explanation as to why or how it could
23 have been mislaid?

24 A. They just think the records had been put somewhere other
25 than where they should have been. That was the best

1 explanation they could give us, and that was by
2 a Chinese doctor who was very difficult to understand.

3 Q. I think you were told that the doctor there would
4 contact you with the results but you still have not
5 received it to this day. Is that right?

6 A. No, we haven't.

7 Q. Was it at that appointment that you found out that
8 ██████████ had had Hepatitis C?

9 A. No, it was before that. It was after he died but before
10 we went to find out the post mortem results.

11 Q. Right. So how did you find out that ██████████ --

12 A. Someone was talking about Hepatitis C. And when I asked
13 if ██████████ had Hepatitis C, he said, "Oh, yes, all
14 the boys have it". So that was the first we knew he was
15 Hepatitis C-positive.

16 Q. When you say that someone, was that a doctor?

17 A. Yes, it was a doctor.

18 Q. So was this a doctor at the haemophilia clinic?

19 A. I can't remember. It was a doctor up at the Royal but
20 which doctor it was ...

21 Q. A doctor at the Royal that you obviously saw after
22 ██████████ had died, at some point told you that?

23 A. Yes.

24 Q. You tell us in paragraph 25, which is WIT0040039,
25 about ██████████'s, about ██████████'s funeral which

1 was attended by his family, friends and representatives
2 of the Scout Association?

3 A. Yes.

4 Q. You tell us there that he was the youngest Scout leader
5 in Scotland?

6 A. Yes.

7 Q. So that obviously played a big part in his life?

8 A. Yes, it did.

9 Q. I take it since you kept his diagnosis to yourself that
10 nobody there knew the cause of his death?

11 A. No.

12 Q. No. What did they think had caused his death?

13 A. It was on his death certificate as pneumonia.

14 Q. The minister talked about his favourite book and quoted
15 a passage from it.

16 In paragraph 26 you tell us that after [REDACTED]
17 died, you were advised to have an HIV test yourself.

18 A. Yes.

19 Q. Had you had one before then?

20 A. No -- oh, yes, I had for the insurance.

21 Q. You say that you had received a needle stick injury
22 whilst you were giving your son medication. Can you
23 remember when that was?

24 A. I had done it quite a few times.

25 Q. Right. So both you and your husband were tested in 1996

1 and you were both found to be HIV negative?

2 A. Yes.

3 Q. You tell us in paragraph 27 about attending bereavement
4 weekends which were organised by the Macfarlane Trust?

5 A. Yes.

6 Q. These were in England. Did you find these helpful?

7 A. Yes, we did, yes. It not only helped us, it helped the
8 other people there as well because they knew -- they had
9 suffered the same situation that you did, that you had
10 someone and you lost them and it was through this.

11 Q. Yes. As you say in that paragraph, it was a weekend
12 without any secrecy, so it was one place that you were
13 able to speak openly and not have the secret that you
14 lived with at home?

15 A. Yes, that's right.

16 Q. If we go on to paragraph 28, you tell us here about the
17 impacts of ██████████'s infection with HIV on your
18 younger son, who was obviously living in the family home
19 at the time you were going through all that we have
20 heard about. You tell us that he was only 14 years old
21 when ██████████ died and that he has been deeply
22 troubled ever since?

23 A. Yes.

24 Q. You say that he suffered from acute depression as
25 a teenager and ██████████'s diagnosis with HIV has had

1 a profound effect on his psychological wellbeing and you
2 feel he is still grieving today?

3 A. Yes, he is. I think he felt he was shut out of the
4 family during all this, that we should have told him
5 sooner, but we felt we were protecting him because he
6 was only 14.

7 Q. Yes. It was a decision that I'm sure you reached very
8 carefully, but you chose not to tell him that
9 [REDACTED] had HIV and when [REDACTED] died, you say
10 that you told him that [REDACTED] had died of pneumonia
11 and you told him in his 20s that [REDACTED] had died as
12 a result of HIV?

13 A. Yes.

14 Q. You feel that with the benefit of hindsight, it might
15 have been better to tell him earlier?

16 A. Yes.

17 Q. But obviously hindsight is a great thing?

18 A. It's a great thing to have.

19 Q. It is, yes. As you say, you did what you thought was
20 best at the time.

21 Was he given any support or counselling--

22 A. No.

23 Q. -- during this time.

24 You tell us in paragraph 30 about deciding to become
25 foster parents?

1 A. Yes.

2 Q. How many foster children have you had?

3 A. I think we have had about seven or eight. We had three
4 children long-term for six or seven years and we had
5 loads of other children in between that needed care for
6 a weekend or overnight. So it's quite a few.

7 Q. A busy household?

8 A. Yes.

9 Q. You feel this helped you through your grief in respect
10 of [REDACTED] just a little?

11 A. I think it helped to nurse it along a bit better, that
12 we had something else to take our mind off it.

13 Q. You tell us in the third line of paragraph 30 that you
14 also discovered that a girlfriend of [REDACTED] was
15 pregnant and you discovered this about a week before
16 [REDACTED] died?

17 A. Yes.

18 Q. You later discovered that [REDACTED] was the father of
19 this child and you have managed to build up
20 a relationship with him, your grandson?

21 A. Yes.

22 Q. This girlfriend had an HIV test which was thankfully
23 negative?

24 A. Yes.

25 Q. [REDACTED] had been practising safe sex with her, was

1 what he told your husband?

2 A. Yes, he was.

3 Q. How old is your grandson now?

4 A. He will be 16 in July.

5 Q. You tell us that you see him regularly and he comes on
6 holiday with you?

7 A. We are going on holiday in two weeks with him.

8 Q. So does he live locally?

9 A. He lives about six miles away from us. So it's quite
10 local.

11 Q. You say that your home is now his second home and his
12 arrival and your foster children helped you cope with
13 your immense grief in respect of the loss of
14 ██████████. He has the same mannerisms as ██████████
15 and you tell us how very proud of him you are.

16 A. Yes.

17 Q. How it makes your day when you see him. Is there
18 anything else you would like to tell us today about the
19 effects of ██████████'s infection with HIV on you and
20 your family?

21 A. I think we have pretty much said it all with the
22 statement we have made.

23 Q. Okay. Well, I appreciate that it must have been very
24 difficult for you to go through this but it has been
25 very helpful for the Inquiry. Thank you very much.

1 A. Thank you.

2 THE CHAIRMAN: Gentlemen, I know that notice was given of
3 matters that were of interest to the other parties. Is
4 there anything that has not been covered?

5 MR DI ROLLO: No, there hasn't, Mr Chairman. All I would
6 like to do is just to thank her on behalf of the
7 patients, relatives and the Haemophilia Society for
8 coming today.

9 THE CHAIRMAN: Mr Anderson?

10 MR ANDERSON: I have no questions.

11 THE CHAIRMAN: Mr Sheldon?

12 MR SHELDON: No questions, sir, thank you.

13 THE CHAIRMAN: It is very difficult -- the impact is
14 obvious.

15 A. Thank you.

16 THE CHAIRMAN: Thank you.

17 (2.25 pm)

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

19

20 CHRISTINE1

21 Questions by MS PATRICK1

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23

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25

