1		Tuesday, 8 November 2022
2	(10.	.00 am)
3	SIR	BRIAN LANGSTAFF: Mr O'Mahony.
4	THE	E WITNESS: Good morning.
5	SIR	BRIAN LANGSTAFF: Welcome, to the Inquiry. Let me
6		explain our arrangements, but, first of all,
7		I understand that because your name, your surname, is
8		mispronounced so often you prefer to be known as
9		Brian.
10	THE	E WITNESS: Correct.
11	SIR	BRIAN LANGSTAFF: Very good name. You're talking no
12		just to the assembled company in front of you, who are
13		a mixture of participants and Core Participants, and
14		potentially in a room beyond this hearing room
15		a breakout room but also online to those who are
16		watching, either on YouTube or on live stream. So
17		the audience for what you have to say will number in
18		three figures, most probably. The questions will be
19		asked by Ms Richards, in a moment, though first, Mary
20		will invite you to take the oath.
21		Mary.
22		MR BRIAN O'MAHONY (sworn)
23		Questioned by MS RICHARDS
24	MS	RICHARDS: Brian, I'm going to start with an overview
25		of your career. You are the current chief executive
		'
1	0	And that's the conscituin which you worked
2	Q.	And that's the capacity in which you worked until 1994?
3	Α.	Correct.
4	Q.	You've sat on multiple committees and boards relating
5	Q.	to haemophilia including, for a period of time, the
6		Irish Blood Transfusion Service board?
7	A.	I still sit on that board, in fact.
8	Q.	You've set those out in your witness statement in
9	۵.	paragraph 3; I'm not going to go through them all but
10		there is a significant number in terms of your
11		involvement.
12		In relation to previous inquiries, you gave
13		evidence at the Institute of Medicine Inquiry in the
14		USA in 1994?
15	Α.	That's correct.
16	Q.	And what, in very broad terms, was the nature of your
17	-	evidence?
18	Α.	The nature of my evidence at the IoM Inquiry was
19		related, entirely, to the response of governments
20		outside the USA. So, they wanted some comparative
21		statistics and data. So really, I was looking at the
22		response in other countries
23	Q.	And then you gave information to the Royal Canadian

8 November 2022 of the Irish Haemophilia Society. 1 2 A. That's correct. Q. And you've held that position since 2006? 3 A. Correct. 4 Q. But your involvement with the 5 6 Irish Haemophilia Society dates back to the early 7 1980s? 8 **A.** 1982. Q. And you've been on the board since 1982 other than for 9 10 a brief period in around 2003-04? 11 Yes. A. Q. You were chairman of the Irish Haemophilia Society 12 13 between 1987 and 2003? 14 Α. Q. Between 1994 and 2004 you were president of the World 15 Federation of Haemophilia? 16 17 Q. And between 2011 and 2019 you were president of the 18 19 European Haemophilia Consortium? 20 A. 21 Q. You yourself have severe haemophilia B? 22 A. Yes. 23 Q. And you're a medical laboratory scientist by 24 background and training? 25 A. Correct. 2 1 Q. -- of a visit that was taking place in Canada not for 2 that purpose? A. That's correct. 3 4 Q. You were involved in the Finlay and the 5 Lindsay Tribunals of Inquiry in Ireland. Just so that we understand the difference between the two: 6 7 the Finlay Tribunal focused on infection through 8 anti-D and also blood transfusion; the Lindsay Inquiry looked at the infection of people with haemophilia? 9 A. That's correct. 10 Q. And you gave evidence to the Lindsay Tribunal twice? 11 12 A. 13 And you then gave evidence to the non-statutory inquiry, the Archer Inquiry, in this country? 14 15 A. Q. I'm not going to ask you in any detail about your work 16 17 in Ireland in the 1980s and '90s, but just so that we 18 can understand the position of the Irish Haemophilia Society at that time, it was, as 19 20 I understand it from your statement, a very small 21 voluntary organisation and in the early '80s it didn't

have an office or even a permanent address?

a voluntary committee, no office, no staff, no

headquarters. In fact, whoever the unfortunate

Yes, when I joined the board in 1982, the Society had

Mounted Police in 1995 in the course of a --

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A.

That's correct.

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- 1 individual was who happened to be honorary secretary,
- 2 all of the mail arrived at their house. So the annual
- 3 budget at the time was around £4,000.
- 4 Q. And it was, I think, 1987 before there was any kind of
- 5 staff member at all?
- 6 Α. We had a part-time member of staff, two mornings
- 7 a week from 1987 and our first full-time staff member
- 8
- 9 Q. Then I just wanted to ask you briefly about your own
- 10 knowledge of AIDS back in the 1980s and how you came
- to be aware of the possibility of a risk of 11
- 12 transmission through blood or blood products.
- 13 Your statement indicates that that came to the 14 attention of the Haemophilia Society in Ireland in
- 15 1983?
- 16 A. Correct.
- 17 Q. And you yourself learnt about it through reading an
- article in a laboratory magazine? 18
- 19 A. Yes.
- 20 Q. So through your own scientific work?
- 21 A. Yes.
- 22 Do you have any recollection of roughly when in 1983
- 23 that might have been?
- 24 March or April of 1983. A.
- 25 Q. Then it was, I think, following a newspaper article,

- 1 head that if we were self-sufficient there would be
- 2 a lower risk of transmission of potentially
- 3 blood-borne viruses.
- 4 Q. In your witness statement, if we just have it up on 5 screen.
- 6 WITN7418001, please, Lawrence, and if we could go 7 to page 5.
- 8 If we pick it up, top of the page, this is
- 9 paragraph 7 of your statement, you've said --
- 10 A. Yes.

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- Q. "In his replies to us ..." 11
- 12 And the context in the previous paragraph was the 13 discussions you've referred to in 1983.
 - "... the treating consultant pointed out that all blood products could potentially cause AIDS or non A non B Hepatitis, and that the risk of bleeding was much greater than the risk from any viral infection."
- 18 Do you have any recollection of when in 1983 that 19 was being said, roughly, by the treating consultant?
- 20 A. That would have been around, I think, May or June
- 21 of 1983, shortly after my meeting with the Blood
- 22 Transfusion Service.
- 23 Q. Then just one other request for clarification from
- 24 your statement. If we go over the page to page 6,
- 25 please. Paragraph 9, you report that:

- and you've referred, I think, in your statement to 1
- 2 the "killer blood" article, which I think dates it,
- 3 for our purposes, to the Mail on Sunday article at
- 4 the beginning of May '83. You then had a meeting with
- 5 the Irish Blood Transfusion Service?
- 6 A. That's correct.
- 7 Q. There was a suggestion that you discuss the issue with
- 8 someone you've described in your witness statement as
- 9 the "treating consultant". Would it be right to
- 10 understand that's Professor Temperley that you were
- 11 talking about there?
- 12 A.
- 13 Q. Again, just so that others can understand your
- 14 statement, what was his role?
- 15 A. Professor Temperley was the national haemophilia
- 16 director, so he was the director of the main National
- 17 Haemophilia Treatment Centre in Dublin at the time.
- 18 The discussions I had were with Sean Hanratty, who was
- 19 the chief scientific officer of the Blood Transfusion
- 20 Service Board, and my meeting with him, which
- 21 I actually took a handwritten minute of, was based on
- 22 the fact that I was concerned that there seemed to be
- 23 little or no progress being made in relation to
- 24 self-sufficiency for factor concentrates from Irish
- 25 plasma. And I was -- you know, I had this idea in my

- "In December 1984 we had the first diagnosis of 2 AIDS in an Irish person with haemophilia."
- 3 A. Yes.

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- 4 Q. And then this:
 - "The indication from the treating consultant at that time was that this may be the only case of AIDS we would see in a person with haemophilia and that perhaps only 1% of those who were HIV positive would go on to develop AIDS."
- 10 Do you know whether any reason was given for that 11 rather optimistic prediction that it might be the only 12 case of AIDS?
- 13 A. I think it seemed to be very much the prevailing
- 14 clinical opinion at the time. Professor Temperley 15 would have had a close relationship with the UKHCDO,
- 16 attended their meetings. If you look at similar --
- 17 people like Dr Peter Jones in his book in 1985 he
- 18 talked about 1, 1.5 per cent. So initially the advice
- 19 was very much that, you know, to stop taking factor
- concentrates was much more dangerous, because there 20
- 21 was risk of bleeding, than the potential risk of
- 22 a potential blood-borne virus. By the end of 1984,
- 23 when we had the first case, I remember
- 24 Professor Temperley saying very clearly that he
- 25 expected this would be the only case we would see,

- 1 that the risk of people with -- who were HIV positive
- 2 going on to develop AIDS was probably 1 per cent. 3
- Q. Can I then just ask you, in terms of the numbers of 4 people with haemophilia in Ireland and numbers
- 5 infected, if we look at a document you've exhibited to
- 6 your statement -- it's WITN7418004 -- we can see it's
- 7 entitled "AIDS, Haemophilia and the Government,
- 8 A submission from the Irish Haemophilia Society
- 9 calling for financial provision for people with
- 10 haemophilia infected with the AIDS virus", and the date is April 1988. 11
- 12 If we could go to page 3, please, Lawrence. We've 13 just got some figures on the right-hand side of the
- 14 page. 15 Α. Yes.

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- 16 Q. Third paragraph:
 - "Of the 296 Haemophiliacs registered in Ireland.
- "- 265 have been tested for exposure to HIV. 18
- 19 "- 106 have been infected with HIV ...
- 20 "- 9 have developed 'full blown' AIDS.
- "- 4 [by that time] have died. 21
- 22 "- 70% of severe Haemophilia A patients have been 23 infected."
 - So the 296 haemophiliacs registered in Ireland, did that encompass, as far as you understand it, those
- 1 emerged following, first of all, a survey that 2
 - the Irish Haemophilia Society undertook of its members
- 3 in 1987; is that right?
- 4 A. Yes, I became Chairman of the Society in 1987, and my
- 5 top priority was helping our members who had been
- 6 exposed to HIV and who had developed AIDS. So, in
- 7 order to understand what their real requirements and
- 8 needs were, a dental surgeon and I -- who sat on our
- 9 board as well -- we did a survey of as many people as
- 10 possible who had HIV and AIDS, so I think we got
- 58 responses out of 70 surveys sent out and that 11
- 12 allowed us to draft up this proposal for Government,
- 13 based on a real understanding of what their needs
- 14 were
- 15 Q. That resulted in the submission that we looked at 16 briefly --
- 17 Α. Yes
- Q. -- a couple of minutes ago? 18
- 19 A. Correct.
- 20 Q. The argument that was being made at that point in
- 21 time, as I understand it, was that there was a moral
- 22 responsibility on the Government to respond to
- 23 the situation of those who had been infected, through
- 24 no fault of their own, with HIV?
- 25 A. Yes.

- who were mild, moderate and severe? 1
- 2 A. No, looking at the numbers, that would probably have 3 been moderate and severe.
- 4 Q. Then we have the figures there, 106 infected with HIV,
- 5 so 40 per cent. Does that remain the figure, as far
- 6 as you know, of the numbers infected with HIV?
- 7 A. Yes, yes.
- Q. Then in terms of the numbers infected with 8
- 9 hepatitis C, do you have any knowledge of what
- 10 proportion were infected with hepatitis C?
- We're talking about 240, 245 people. 11 Α.
- Q. Okay. So a very significant proportion? 12
- 13 Yes, but also that would have encompassed a number of 14 people with mild haemophilia as well.
- 15 Q. Understood. We can take that down, thank you.
- 16 I want to ask you now, Brian, about some of
- 17 the measures that have been put in place, over
- 18 the decades in Ireland, to address the needs and
- 19 the circumstances of those who were infected through
- 20 contaminated blood and blood products. The purpose,
- 21 as I know you understand, being for us to understand
- 22 whether there is anything that can be learnt from how
- 23 Ireland has responded to the plight of those infected.
 - So I wanted to start with the Haemophilia HIV
 - Trust. As I understand your statement, Brian, this
- 1 Q. That wasn't accepted by the Government to start with
- 2 and the Society embarked upon a public and political
- 3 campaign?

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- 4 A. I mean, when you say it wasn't accepted, all we
- 5 received, actually, was an acknowledgement of receipt
- 6 of the document and then five months of silence. And
- 7 despite the fact I was naive enough to think, at
- 8 the time, that if you sent in a well reasoned,
- 9 well argued case that it would receive a fair response
- 10 from the Department of Health, that didn't happen. So
- 11 at the end of that year people were getting sicker and
- 12 they were dying, so we realised we had no option
- 13 really but to try and put political and media pressure
- 14 on the Government to respond to this.
- 15 Q. Now, that resulted, eventually, in an agreement which
- 16 led to the establishment of the Haemophilia HIV Trust?
- 17 Α. Yes

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- 18 Q. Did you -- what was your understanding of what
- ultimately persuaded the Government to accede to that? 19
- 20 A. Well, the fact that the political media campaign was
- 21 very successful, we got a lot of traction, a lot of
- 22 media coverage, we had some of our members with HIV
- who spoke publicly and very bravely to highlight 24 the issue. And then it went all of the way to -- we
- 25 had a minority Government at the time -- it went all

of the way to a vote in Parliament.

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The week before the vote I had assumed that the Government would offer some sort of compromise. We spent the week in discussions, the Government didn't move whatsoever on this. They made it an issue of financial management so that when -- they then threatened that if they lost that vote in the Parliament they would call for an election. So the Prime Minister lost the vote in Parliament, called a general election, lost seats in the election, and fortunately, in the course of the election campaign, we had received written commitments from the leaders of all of the other parties to implement a trust fund if they got into office. The outgoing Prime Minister then had to go into a coalition with another party and, as part of the negotiations for the programme for Government, the trust fund was established.

- Q. Now, initially, that trust paid regular payments, so
 from about 1987 to 1991 there was some regular
 payments?
- 21 A. 1989 to 1991, it was established in '89. We made regular payments to some individuals, not to all individuals. It was very much based on an assessment of individual need and people's individual circumstances, and people really were struggling, some

1 to be done as quickly as possible; is that right?

A. Yes, it was very non-complicated. I think the Society had people on the board of trustees with independent trustees. So a request would come in for funding, it may be based on a phone call, it may be based on a letter and then that would be discussed very, very quickly and a decision made. In some cases where it was a very urgent situation and the request came in directly to the Irish Haemophilia Society, we would pay the item ourselves and then seek to recoup the money later from the HHT.

If you look at our audited accounts for all the years from 1989 to now, there is always an in and out from the HHT and they never match up because, typically, there can be a couple of months' delay before recouping the money back. But it's always been our view that the trust fund should be non-complex, it should be easy to administer and that payments should be made quickly where they're required. In fact the procedures were set up following meetings with the beneficiaries, so that was very important. They were consulted on how they wanted the trust fund to operate.

Q. Now, in 2002 there were further payments made, we'll
 come on to that, but the Tribunal that had been set up

1 people were really struggling. So regular payments

2 were made to those who needed them until 1991 when, in

3 fact, a further tranche of compensation was paid.

- 4 Q. Those are the *ex gratia* payments, essentially, from 1991?
- 6 A. Yes, yes.
- 7 Q. We'll pick up those in a moment. If we then -- just
- 8 staying with the Haemophilia HIV Trust, from 1991
- 9 onwards it was one-off payments?
- 10 A. Yes.
- 11 Q. So it might be for funeral grants or equipment, those12 kinds of --
- 13 **A.** Yes. Hospital beds, wheelchairs, any -- special
- 14 mattresses, anything that would be required by
- the person with HIV or AIDS to help them to deal with
- the condition or -- and certainly one-off items which
- would not easily be provided, in any sort of timely
- 18 manner, by the Health Service.
- $19\,\,$ Q. And what you've told us in your statement is that
- 20 the way it was designed to operate was that it didn't
- 21 have overly complex procedures, or requirements for
- 22 lots of different types of proof. The individual
- 23 would communicate with the trust, it might be by
- 24 letter or by telephone, and a decision would be made
- as to whether to make the payment, and it was designed

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- 1 in relation to hepatitis C was extended to cover HIV?
- 2 A. Yes.
- 3 Q. And as a result there was a decision that needed to be
- 4 made about the future of the Haemophilia HIV Trust?
- 5 A. Yes.
- 6 Q. As I understand it, the decision was taken through
- 7 consultation with those who had been infected; is that
- 8 right -- with a range of beneficiaries?
- 9 A. Yes, we organised a meeting with as many of those as
- 10 possible who survived with HIV and we asked them --
- 11 you know, at that point there wasn't an enormous
- 12 amount of money left in the trust fund so we offered
- them the option of closing down the trust fund and
- 14 dividing the remaining funds equally between
- the participants, or keep it going as sort of an
- 16 emergency fund, and they were very adamant they wanted
- 17 it kept going.
- 18 Q. That's the way in which it has continued to operate,
- again, through -- it continues, is this right, to make
- 20 one-off --
- 21 **A.** Yes, yes.
- 22 Q. -- payments? Again, it might be for equipment or --
- you refer to Christmas payments?
- 24 A. Yes, we also look very carefully at, you know,
- 25 the people's individual circumstances, and we make

- 1 a number of payments at Christmas each year to
- 2 individuals who we believe are still in particular
- 3 financial need.
- 4 Q. And there was a top-up of the amount that the trust
- 5 had in 2006?
- 6 A. Yes, yes.
- 7 Q. EUR 300,000?
- 8 A. Yes, that's right.
- 9 Q. The trust was chaired initially by one High Court
- 10 judge and then since then has been chaired by another
- 11 High Court judge?
- 12 A. Yes.
- 13 Q. You tell us in your statement that they had met with
- 14 a lot of those who were infected, but, you know, they
- 15 also made themselves known to the community?
- 16 A. Yes.
- 17 Q. Is that right?
- 18 A. Yes.
- 19 Q. And how important has that been?
- 20 A. Both Judge Carroll and latterly Judge Murphy, we had
- 21 several meetings with the members who had HIV to hear
- about their concerns and their issues, and also both
- chairs of the trust would usually attend our annual
- 24 conference for the full weekend and meet members and
- 25 just have conversations with them. So they really
 - 17

1 A. Yes.

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- 2 Q. -- in the United Kingdom, which was settled in 1991;
- 3 is that correct?
- 4 A. That's correct. We employed a legal team from 1989
- 5 and worked with them and we were looking at
- 6 the Society actually funding a test case. But as this
- 7 was going on and on through the course of 1990, it
 - became apparent this was not going to see a courtroom
- 9 at any time in the immediate future and in the
- 10 meantime the number of people dying of AIDS and
- 11 getting AIDS was increasing rapidly. We then saw that
- 12 the -- the compensation paid by the John Major-led
- 13 Government in the UK, and we decided the time was
- 14 right to try and settle this politically. So at
- 15 the time the minister asked the Society for
- 16 a submission to settle these legal cases and we
- 17 entered, again, into a four or five-month political
- and media campaign, culminating in an offer of
- 19 compensation in 1991.
- 20 Q. That resulted in what I think you've described as
- 21 tiered payments --
- 22 A. Yes.
- $\,$ 23 $\,$ Q. $\,$ -- in a way that's a similar but not identical, but
- 24 similar to the way in which it was done in the
- 25 United Kingdom?

- 1 developed empathy and a sense of understanding of
- 2 the real issues in the community.
- 3 Q. And you were asked in your statement if you thought
 - that the HIV -- the Haemophilia HIV Trust, the HHT,
- 5 had been successful, and you've told us in your
- 6 statement that you think it has been, its objectives
- 7 were met, and you've identified three factors:
- 8 trustees acting with empathy and understanding;
- 9 the ability to respond rapidly; and its relatively
- 10 informal structure?
- 11 A. Yes.

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- 12 Q. Is that right?
- 13 A. Yes.
- 14 Q. So that's the HHT.
- 15 **A.** Mm.
- 16 Q. Now, the second main plank of financial support for
- 17 those who were infected is the compensation tribunal,
- and so I just wanted to ask you a little about how
- 19 that --
- 20 A. There was the earlier 1991 -- (overspeaking) --
- 21 Q. I'm sorry, yes --
- 22 A. -- as well, yes.
- 23 Q. Yes. Yes, let's pick that up.
- 24 So there was litigation in Ireland in the same way
- 25 as we know that there was litigation --

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- 1 A. Yes.
- 2 Q. So if we look by at your statement, please.
- 3 WITN7418001, page 24.
- 4 It's paragraph 43, and you've set out in the
- 5 previous paragraphs the process of the litigation, the
- 6 campaign and so on.
- 7 A. Yes.
- 8 Q. "We secured an improved offer of £8 million, to be
- 9 paid quickly and with no £1 million claw back."
- That was a clawback of what had been paid to the
- 11 HHT, was it?
- 12 A. Originally the Government offer was 7 million, and
- from that 7 they also wanted to claw back
- the 1 million paid to the HHT in 1996, and they wanted
- to stage the payments over a two-year period. So
- 16 frankly, in the week between that 7 million and
- the improved offer, local elections were taking place
- a week later, we knew we had one more week to optimise
- our political and media campaign, we actually had four
- candidates running in the local elections, so we
 secured a better offer of 8 million and with no
- 22 clawback. So in fact it was an increase of 2 million
- over the previous offer and it was paid over a course
- 24 of two or three months.
- 25 Q. Then we can see the figures that were agreed there.

- 1 **A.** Yes.
- 2 Q. So a married man with children, 101,000; widow,
- 3 93,000; married man with no children, 89,000;
- 4 single adult or child, £76,000; infected spouse,
- 5 25,000, although there were in fact none; and then
- 6 non-dependent relatives of a deceased man, 21,000.
- 7 So if we look at the position as at the end of
- 8 1991, you have those one-off ex gratia payments?
- 9 **A.** Yes.
- 10 Q. Then you have the operation of the HHT?
- 11 A. The HHT, yes.
- 12 SIR BRIAN LANGSTAFF: May I just ask a couple of questions
- 13 at this point.
- 14 First of all, the paragraph that we see on the
- 15 screen uses the pound symbol.
- 16 A. Well, we didn't change to the euro until, I think,
- 17 2006.
- 18 SIR BRIAN LANGSTAFF: So though this is punts?
- 19 A. Punts, yes.
- 20 SIR BRIAN LANGSTAFF: At this stage a punt was approaching
- 21 parity, was it?
- 22 A. It was equivalent to sterling, I think, at the time.
- 23 SIR BRIAN LANGSTAFF: So for the £8 million pounds, as
- 24 near as makes little difference, we can read that as
- 25 £8 million sterling?

- 1 discussions about the availability of Interferon and,
 - indeed, people being charged for treatment with
- 3 Interferon?

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- 4 A. That's correct. Obviously, when the hepatitis C virus
- 5 was identified in 1989, it became a topic where --
- 6 which we discussed out our conferences in '89, '90,
- 7 '91, '92, we were doing quite a bit of work on this,
- 8 and the first treatment for hepatitis C, Interferon,
- 9 there was actually a monthly charge for this, which we
- 10 felt they should certainly not be charging to people
- 11 who had been infected through blood products supplied
- 12 by the state. So we had a series of meetings with
- the Health Ministry to discuss removing that charge
- for people with haemophilia, and we also initiated
- 15 discussions on compensation at that point.
- 16 Q. If we could just put your statement back on screen,
- sorry, Lawrence, 7418001, and go to page 25. In
- 18 paragraph 46 you say this:

19 "Following many discussions, it became clear that 20 the Department of Health were willing to concede in

- 21 principle on the issue of compensation."
- Then you go on to talk about how the Tribunal came
- 23 to be set up -- and I'll come on to that -- but what
- 24 was your understanding or impression of why it was
- 25 that the Department did ultimately agree to

A. Yes.

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- 2 SIR BRIAN LANGSTAFF: This is for a country with
- 3 a population at the time of that about 3.5 million.
- 4 A. That's correct, yes, that's correct.
- 5 SIR BRIAN LANGSTAFF: So if -- to do the maths more
- 6 quickly, assume 4 million, there are 60 million people
- 7 roughly, a bit more, in the UK, so in order to
- 8 translate this into what would be an equivalent
- 9 payment in the UK, you'd have to multiply 8 million by
- 10 15.
- 11 A. 120.
- 12 SIR BRIAN LANGSTAFF: 120 million. That was what was paid
- on the basis of a moral obligation and nothing else.
- 14 A. Yes. correct.
- 15 SIR BRIAN LANGSTAFF: Thank you.
- 16 MS RICHARDS: And is it right to understand that there was
- 17 no acceptance of liability, of legal liability, by
- 18 the Government?
- 19 A. That's correct.
- 20 Q. Now, as your statement then describes to us, what then
- 21 came to the forefront was the position of those who
 - 22 had been infected with hepatitis C?
- 23 A. Yes.

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- 24 Q. And you described that particularly coming to your
- attention in I think, 1993, when there were

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- 1 the establishment of what was initially going to be
 - a non-statutory but became a statutory Tribunal?
- 3 $\,$ A. I think certainly there was discussion -- that we had
- 4 many, many discussions with them, but it was --
- $\,\,$ the atmosphere was different than in '89 and '91. We
- 6 were not getting the same resistance -- absolute
- 7 resistance that we were getting in '89 and '91, when
- 8 it was like trying to get blood from a stone frankly.
- 9 They were a bit more open to the issue, they were
- a bit more open to the discussion. And, in hindsight,
- 11 I think that's because they were aware that they had
- this infection of over 1,000 women with anti-D in
- 13 the background, and that came to the fore in February
- of 1994. So I think they saw this was going to be
- 15 a wider issue and they needed to deal with this.
- 16 Q. So the Department agreed to set up a hepatitis C17 compensation tribunal, and that became a statutory
- 18 tribunal under the Hepatitis C Compensation Tribunal
- 19 Act of 1997. If we just look briefly at that.
- 20 WITN7418010.
- So we've got the arrangement of the Act there. If we go, please, to page 4, we can see, bottom of the
- 23 page, section 3 establishes the Tribunal:
- 24 "... a Tribunal to be known as the Hepatitis C
 - Compensation Tribunal to award compensation ..."

And to a class of claimants.

Now, just before we look at who could claim from this Tribunal, this uses the term "compensation" rather than "ex gratia payments", so was that significant to your mind, that this was an acceptance of compensation, rather than the making of a payment to dispose of litigation?

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9 the time in relation to hepatitis C infection, and
10 the word "compensation" was used very clearly by
11 Government and, in fact, they're not going to put
12 the word in an Act without thinking it through,
13 whereas in 1989 the word was banned, they talked at

A. Yes, because there was no litigation ongoing at

whereas in 1989 the word was banned, they talked about recompense or *"ex gratia"* payments without admission of liability. "Compensation" was clearly understood to be compensation in --

17 Q. But there was still no acceptance of legal liability18 by the Government?

A. That's correct. And in fact it's worth, I think,
 reiterating that the compensation tribunal -- that
 the first payments under the compensation tribunal
 were made a year before the Lindsay Tribunal terms of
 reference were even -- the discussions started
 four years before the tribunal started hearings and
 six years before the report. So I think they had

1 a prima facie entitlement to compensation? 2 A. That's correct. And, in fact, in the case of a person 3 with haemophilia, just being able to show, from 4 medical records, that the person had received factor 5 concentrate -- plasma-derived factor concentrate, was 6 deemed sufficient proof. And I think, yes, there 7 was -- in relation to negligence, if the individual 8 believed that they were entitled to aggravated or 9 exemplary damages they could look for that or, instead 10 of that, they could also -- any award that they would get would be topped up by 20 per cent from a so-called 11 12 reparation fund.

13 Q. That's how we understand -- the reference
14 to section 5, subsection (3) there, is a reference
15 to -- if we go to the bottom of the next page, it's
16 the third paragraph from the bottom:
17 "An award in respect of aggravated or exempted."

"An award in respect of aggravated or exemplary damages may be made by the Tribunal where a claimant establishes a legal entitlement to such against a relevant agency or the Minister."

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21 **A.** Yes.

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Q. So if a claimant wanted aggravated or exemplary
damages, they had to establish that there was a basis
for it that was a basis recognised in law. But is
this right, they could opt then, instead, for

clearly -- I think the Government put their hand up
 and accepted responsibility at that point. Yeah,
 there was no legal admission of responsibility but,
 clearly, they were paying compensation.

Q. And if we go over to page 6, we've got Section 4 of
the Act, and that tells us who could claim, initially,
to the Tribunal?

8 **A.** Yes.

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Q. So those diagnosed positive for hepatitis C resulting from anti-D, those diagnosed with positive for hepatitis C as a result of receiving a blood transfusion or blood product, and then we have children and spouses, carers, and dependants.
 If we just go to the next page, just to pick up

If we just go to the next page, just to pick up something, it's in subsection 7, so it's the fourth paragraph down:

"... a claimant shall not be required to produce to the Tribunal any evidence of negligence of the part of a relevant agency or other person in respect of her or his claim."

So there was no investigation by the tribunal of liability. The claimant had to establish that they had been infected through either anti-D or blood or blood products provided by the state, but that was all they needed to show in order to establish

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a 20 per cent uplift to their compensation?
 A. That's correct. Any individual who felt that they
 were entitled to aggravated or exemplary damages could
 seek those as part of their hearing. If they decided

5 not to seek that, their award was automatically topped up by an additional 20 per cent.

Q. And that came from something called the ReparationFund?

9 **A.** Yes.

10 Q. What was that?

11 A. It was basically a fund that topped up the awards by
12 20 per cent, in lieu of aggravated or exemplary
13 damages.

14 Q. But essentially a fund from the same source, from15 Government?

16 A. Yes. Absolutely, yes.

17 Q. Then we can take the --

SIR BRIAN LANGSTAFF: Just before we do that, can we go
 back to page 6, please, the list of those who can
 claim? Under Section 4, 4(c) is a child or any
 spouse, and (d) a person who is responsible for
 the care of a person referred to in (a), (b) or (c).

23 So that suggests to me, on the language, that that

24 would include parents of children affected. Is that

the way it worked?

1 A. I believe so, yes. Yes.

2 SIR BRIAN LANGSTAFF: Thank you.

3 MS RICHARDS: I skated, sir, over subparagraph (f),

"a person referred to in section 9"; that refers to the power of the minister to extend the classes of

persons who could bring claims.

So if we then go back to how the Tribunal operated as set up under the 1997 Act, so the claimant had to prove they had an infection caused by treatment from the state on the balance of probabilities. And as you've explained, for those with haemophilia, that was a relatively straightforward exercise?

13 A. Yes.

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14 Q. I don't know whether you know the answer to this 15 because obviously your focus will have been those with 16 haemophilia, but we have heard evidence in relation to 17 the United Kingdom of claims being made to the funds 18 established here for -- by those infected through 19 transfusion being difficult to establish because of 20 lost or missing or incomplete medical records.

> Do you know whether that was a problem in Ireland for those infected through the transfusion route?

A. Not that I'm aware of, and certainly we had quite a lot of dealings with Transfusion Positive, the group who represent people who got hep C through blood

1 they could then go back to the tribunal for a further 2 award. So I think a number of people -- also some of 3 the younger claimants whose career path had not been 4 set, where the impact of the hepatitis C on their 5 medium to long-term future could not be wholly 6 ascertained, would often have a provisional award and

then go back later on for a full award.

8 Q. Is it right to understand that the approach that 9 the tribunal was required to take to the assessment of 10 compensation was to apply the same approach that 11 the courts would apply in a claim, a tortious claim,

12 for damages for personal injuries?

completed, yes.

13 Α. Yes, my clear understanding is that the tribunal was 14 assessing damages. It was as if you had won a court 15 case and there was purely an assessment of damages. 16 So there was no talk about liability or negligence, it 17 was purely -- it was as if a court case had been 18

19 Q. Then in terms of legal representation, the costs of 20 legal representation were met through this process?

21 A.

22 Q. So those who were making the claims had the benefit of 23 lawyers to assist them in advancing their claim?

24 A. Yes. When the tribunal started in 1995, we had 25 a meeting with the members who agreed to go down 31

transfusion. I hadn't heard that raised as an issue. 1

2 My understanding, again, is that the Government took

3 the view that, you know, if you had haemophilia and

4 you'd been treated with your factor concentrate or

5 cryoprecipitate and you got hep C, that was the cause.

6 If you could ever show that you had a blood

7 transfusion, that was sufficient cause. And if you

8 had received anti-D in one of a number of particular

9 years, that was the cause.

10 Q. Then is it right to understand that the claimant 11 making the claim to the compensation tribunal could

elect for a lump sum, so an assessment of their

13 compensation once and for all, or for provisional

14 damages?

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15 A. Yes, the majority elected for a one-off lump sum 16 award, but there was also the option to take an

17 initial award, especially if the individual was

18 concerned about progression of liver disease or what

19 they were facing in the future. And then there would

20 be specific wording in their tribunal award which

21 would allow them to go back for further compensation

22 in specified circumstances. For example, an

23 individual who had cirrhosis might have wording in his

24 award saying that if he or she required a liver

25 transplant and there were costs associated with that,

1 the route of a tribunal. They also agreed that the

Society should engage a legal team who would act on

3 behalf of any member who wanted them to act on their

4 behalf, and that we would also search out expert

5 witnesses that many of them could use. So they really

6 relied on us to find a legal team and to find a lot of

7 expert witnesses.

> Now, of course, any individual was entirely free to get their own legal team and their own expert witnesses, but vast majority used the same legal team and used the same expert witnesses, which actually was really helpful because they quickly developed a level of expertise and skill on this.

14 Q. Then there was a right of appeal against 15 the Tribunal --

16 **A**. Yes

17 Q. -- award to the High Court?

18 A. That's correct.

19 Q. And is it right to understand that in the early years 20 there were a number of appeals because it was thought

21 that the tribunal assessments were too low?

22 A. Yes.

23 Q. Did that have the effect essentially of raising them 24 overall for the future or has the need to appeal to

25 the High Court continued to occur regularly?

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- A. It continues, perhaps not to the same extent. I mean 1 2 when the vast, vast, majority of appeals to the High 3 Court resulted in a significant increase in the award. 4 So I think that did start the tribunal thinking in 5 terms of giving higher awards. So perhaps the 6 number of appeals diminished but there were still 7 appeals. 8 Q. Now, this obviously covered hepatitis C only, but in 9 2002 the tribunal's remit was extended to encompass 10 HIV?
- 11 A. Yes.
- 12 Q. How did that come about?
- 13 A. In 2002 we had an election coming up, again, and we'd 14 had the hearings of the Lindsay Tribunal, including 15 the very powerful public testimony of members, during 16 the course of the tribunal, and in the two years 17 leading up to the tribunal and during the course of 18 the tribunal we had constant meetings with Government 19 on various issues. But one of the things was pressing 20 for was that we felt that the 1991 awards, while very, 21 very welcome at the time, were -- were -- they were 22 not fair and equitable compensation for people who 23 got HIV. We felt, really, that those individuals had 24 been shortchanged, and in particular -- in 25 particular -- the families of those who had passed
 - that:

2 "New areas of claim were introduced under the 3 [2002] Act ..."

4 A. Yes.

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- Q. "a. [Child], spouse, father or mother of those who had died could claim under loss of society or psychiatric injury including post-traumatic stress disorder;
 - "b. Partners or spouses of those infected could claim under loss of consortium;
 - "c. Children or spouses of those who died could claim for loss of society ([so] loss of [the] ... care, companionship or affection);
 - "d. Dependents could also claim for aggravated or exemplary damages ..."

Where there was a legal entitlement that could be established.

17 These extensions covered both HIV and hepatitis C?

18 A. Yes, correct.
19 Q. So the significance of the 2002 Act -- is this
20 right -- is twofold. First of all, it establishes, or
21 extends the rights that were conferred by the 1997 Act
22 to those infected through HIV, and then it provides
23 for a wider range of types of claim that's applicable
24 to both those infected with hepatitis C and those

infected with HIV?

away prior to 1991.

So it basically came about, I think, as a result of our discussions with Government and, frankly, the public impact of the very powerful public testimony at Lindsay.

Q. So if we go back to your statement, so WITN7418001,
 pages 28 to 29. If we start at the bottom of page 28,
 we can see there was an amendment to the 1997 Act
 through the Hepatitis C Compensation Tribunal
 (Amendment) Bill, 2002.

Then if we go to the next page, you've listed in paragraph 59 those who could apply for compensation following the amendment. So, similar to what we've seen previously, but now encompassing HIV and the children or spouses of those infected with HIV, dependants and carers, HIV as well as hepatitis C?

A. Yes. And I think the significant part of that for us,

17 A. Yes. And I think the significant part of that for us18 really, was if you look at the section e, that the:

"Widows or Dependants of those who had died."
So the individual was no longer disadvantaged by
the fact that they'd passed away prior to the 1991
Act, their families were getting the full compensation
that they would have been entitled to had they
survived to that point.

25 Q. Then if we go to the next paragraph, you tell us also

1 That's correct, and bear in mind, however, that all of those were infected with HIV were also co-infected 2 3 with hepatitis C, so they had been compensated 4 previously through the '91 settlement, but also 5 through the 1997 Hepatitis C Compensation Tribunal 6 Act. But this broadened it, really, to give more 7 compensation to people with HIV and, particularly, to 8 the families of those who had passed away.

- Q. In terms of assessment for loss of earnings, which is
 one of the heads of claim that can be advanced to
 the tribunal --
- 12 **A**. Yes
- 13 Q. -- do you know how the tribunal typically assesses14 the loss of earnings?
- 15 **A.** I think they bring a number of expert witnesses, they look at the person's educational record, they do
 17 IQ tests, they look at the career path they may have had without hepatitis C. There may be opportunities that the individual may have had to pass up on due to the hepatitis C, or HIV. So it's basically based on an assessment. There might be an educational
- psychologist and a couple of expert witnesses.Q. Then in terms of those who are bringing a claim as
- 24 a carer --25 **A.** Yes.

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- Q. -- effectively for the care that they will have 1 2 provided, gratuitously, to a relative, how is that
- 3 cost of care assessed? Do you know?
- 4 A. I can't answer that, no.
- 5 Q. In terms of the aggravated and exemplary damages or
- 6 the 20 per cent uplift, have there been many cases in
- 7 which claimants have opted to try to establish an
- 8 entitlement to aggravated or exemplary damages?
- 9 A. Not that I'm aware of, no.
- 10 Q. So claimants have typically gone for the 20 per cent 11 uplift?
- 12 A. Yes, yes.
- 13 Q. In terms of who sits on the tribunal, I don't mean by
- 14 name, but what are the kind of -- what kind of
- 15 individuals are appointed to the compensation
- 16 tribunal?
- 17 **A.** They tend to be barristers, all of them.
- Q. How important has the availability of legal 18
- 19 representation been for the success of the tribunal in
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- 21 A. Vital. I think the availability of legal expertise
- 22 and expert witnesses has been absolutely vital,
- 23 because if you have across the board payments, as we
- 24 had in '91, then you really don't need that, but when
- 25 you're having an individual assessment, each

- 1 A. It's very daunting for individuals with haemophilia
 - who have been exposed to HIV or hepatitis C to have to
- 3 stand up or sit down at a legal hearing and make their
- 4 case. So even preparing for a non-adversarial hearing
- 5 was very, very difficult for many of them because it
- 6 means revisiting all the trauma, all of the issues
- 7 over the years. It was really helpful that, from 8
 - day one, the tribunal was -- it was sympathetic, in
- 9 terms of the way that the individuals were dealt with.
- 10 It wasn't -- it wasn't adversarial in terms of
- 11 the questioning.

They would, of course -- there would be questions, they would question the figures, they would question some of the financial statements and so on, but it was non-adversarial for the most part. That has continued for the most part.

Now, in the last couple of years, now the vast majority of the cases -- primary cases, have been heard. My understanding is the last year or two, during Covid especially, it's become a little more adversarial, they are trying to limit the number of witnesses. Obviously they're doing virtual hearings and they're questioning more. But I think that, for the vast majority of our members going through the tribunal, it was genuinely non-adversarial.

1 individual's circumstances are going to be different, 2 their experience is going to be different, their life 3 with hepatitis C or HIV or both is going to be

different, the impact on their life is going to be

different, so I think you really need an expert team 5

6 to put that in place.

It's a legal process, so, you know, the vast majority of individuals would have no idea how to approach that, and there is a lot of structure involved in terms of putting the case, you know, getting it prepared. So I think you do need a legal team, you need expert witnesses, and frankly, their costs -- it's been very, very helpful that their costs

13 14 have been borne by the state as part of the process.

15 Q. You've set out your view in your statement that

16 the tribunal has been a success?

17 Α.

18 Q. And again, you've identified, I think, a number of

19 the factors. One, the availability of excellent legal

20 support. Another, the availability of excellent

21 expert witness support. You've also identified

22 the non-adversarial nature of the tribunal, although

23 you've suggested that there might have been a shift in

24 that regard. Can you just help us understand a little

25 more about that?

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- 1 So we can understand the typical pre-Covid process --
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- Q. -- so a written application would be submitted --3
- Yes. 4 A.
- 5 Q. -- is that right?
- 6 A. Yes.
- 7 Q. And that would set out, essentially, the basic facts
- 8 about the claimant, and then would that written
- 9 application be accompanied by supporting expert
- 10 evidence?
- 11 A. Yes, there would be a written application. There
- 12 would be proof from the medical records that
- individual had been exposed to hepatitis C or HIV 13
- 14 through blood or blood products. There would be
- 15 a summary, I guess, of their medical records. There
- 16 would typically be a report from the haematologist who
- 17 treated them and the hepatologist or infectious
- 18 disease consultant who were treating them for HIV or
- 19 hepatitis C respectively.

20 There would be -- usually the individual going to 21 the tribunal would be asked by the legal team to 22 draft, basically, an essay on the impact of

23 hepatitis C or HIV in their life. They would draft

24 that, that would be included.

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There would be reports on loss of earnings, there

- 1 would be reports on the impact on their life, there
- 2 would be a report from an educational psychologist,
- 3 and also a counsellor who was specifically employed by
- 4 the legal team, there would be a psychological
- 5 assessment. So there would be quite a lot of reports
- 6 going in.
- 7 Q. So those would all be submitted to the tribunal?
- 8 **A.** Yes.
- 9 Q. Would there then always be a hearing in every case, or
- 10 could an assessment be made on the basis of
- 11 the written material?
- 12 A. I'm not -- I think a hearing was -- in every case
- 13 there was a hearing.
- 14 Q. In terms of the structure of that hearing, there would
- be the claimant, their legal representative. Would it
- 16 always be necessary for all the experts to come and
- 17 give oral evidence?
- 18 A. No, not necessarily. Very often the expert's written
- 19 evidence would be read into the record and taken as
- 20 read
- 21 Q. Would it be right to understand that there would be no
- 22 other side represented? There would be no opposition
- 23 to the claim? Or was there someone there representing
- the Department or the Government?
- 25 A. There was usually somebody there from the Department
 - 41
- 1 the questions were usually directed to the legal team
- 2 or to the expert witnesses but very rarely to
- 3 the individual giving evidence on their own behalf.
- 4 Q. Would the Department make competing submissions? So
- 5 if you have got the claimant's representative making
- 6 a submission as to how the loss of earnings should be
- 7 calculated and what figure the tribunal should award,
 - would you have the Department making submissions to
- 9 say, "No, no, it should be a lesser figure"?
- 10 A. Not that I'm aware of, no. You could, perhaps, check
- 11 that with the legal team we had, but not that I'm
- 12 aware of, no. I think they would -- they may question
- 13 the submission that was made, but they wouldn't
- 14 normally submit an additional submission of their own.
- 15 Q. Now, in terms of the success of that process, in
- 16 addition --

- 17 SIR BRIAN LANGSTAFF: Just before we go to that, can I ask
- 18 another question about the process? What you've
- described is very similar to a court assessing an
- amount of compensation, with one exception. In
- 21 a court, as counsel has pointed out, there are, of
- 22 course, two sides, just as there are in your tribunal,
- 23 where the Department of Health has an interest as
- 24 the paying party, but there is very often, if
- 25 the issue is just -- I say "just" -- the amount, there 43

- 1 of Health -- I guess keeping an eye on the public
- 2 finances -- but that was it really, there was no
- 3 adversarial people there. But the Department of
- 4 Health were usually represented. The legal team,
- 5 the individual, perhaps their family member -- before
- 6 the hearing there would often be somebody from
- 7 the Society -- one of my team might be with them
- 8 outside just to help them through the day, help them
- 9 make arrangements and so on.
- 10 Q. To what extent did the individual have to give
- 11 evidence to the tribunal in the hearings? Was that
- 12 always the case?
- 13 A. It wasn't obligatory but the vast majority of cases,
- 14 they gave evidence.
- 15 Q. So would the tribunal be composed, then, of one
- 16 member? There would be a single lawyer --
- 17 A. Usually, three, usually, yes.
- 18 Q. Usually three?
- 19 **A.** Yes.
- 20 Q. And they would ask -- or could ask questions?
- 21 A. Yes.
- 22 Q. But did whoever was there representing the Department,
- 23 did they play an active role in the proceedings,
- 24 asking questions?
- 25 A. They did at times, yeah. Yes, they did, yeah. But

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- 1 can be settlement of a claim beforehand. There was,
- 2 of course, settlement of your litigation in Ireland
- 3 beforehand. Is there any history of the Department
- 4 saying, "Well, we've read the written submissions,
- 5 we're making an offer", and the individual saying,
- 6 "Well, that offer looks good to me"?
- 7 **A.** No.
- 8 SIR BRIAN LANGSTAFF: So there is no settlement process in
- 9 this at all?
- 10 A. No, not that I'm aware of, no, I haven't heard of that
- 11 at all.
- 12 **SIR BRIAN LANGSTAFF:** Thank you.
- 13 MS RICHARDS: In terms of the success of the scheme, as
- 14 well as the features you've identified, would it be
- right to understand that perhaps the major hallmark of
- success has been that it's resulted in the payment of
- 17 substantial amounts of compensation to those who were
- infected and whose lives were devastated as a result?
- 19 So they have received an award which is deliberately
- designed to compensate them for their losses?
- 21 A. Yes, I think that's fair. But also I think --
- 22 I wouldn't underestimate the importance of
- the individual having their day in court, having their
- 24 hearing, having their individual circumstances, you
- know, investigated and looked at and a decision made,

- as opposed to just being part of a group. 1
- 2 Q. So it's an element of individual recognition?
- 3 A. Yes.
- Q. The recognition of the impact there has been on that 4
- 5 individual's life?
- 6 Α. Yes.
- 7 Q. In terms of the disadvantages of the scheme, would it
- 8 be right to understand that the major downside has
- 9 been the length of time it has taken for some cases to
- 10 be finally resolved?
- A. Yes, I mean, I think the process has been very good 11
- 12 for the vast majority of people but some cases have
- 13 taken several years to get to a hearing. If
- 14 the individual who was infected was a child, then you
- 15 can't really ascertain their loss of earnings or their
- 16 future potential career possibilities for many, many
- 17 years, so there may be a provisional award, an award
- 18 later, and that has meant that the process has taken
- 19 quite a long time for some people. And, you know,
- 20 even though it's a very good process, it does delay
- 21 closure. So until an individual has finished entirely
- 22 with the compensation tribunal, it's kind of hard to
- 23 bring some closure to the issue. So I think that's
- 24 the -- the big disadvantage is the time required.
- 25 Q. And has there been any expressions of dissatisfaction

- 1 any sense of how long typically, from the making of
 - the claim to the tribunal award, how long a period
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- 4 A. I mean, an educated guesstimate would be a year to
- 5 18 months. Some cases significantly less than that,
- 6 some cases significantly more than that.
- SIR BRIAN LANGSTAFF: May I ask, are there cases 7 8
 - continuing to this day?
- 9 A. Yes, and they tend to be primarily secondary cases:
- carers, family members, maybe loss of society, loss of 10
- 11 consortium, psychiatric injury. So the vast majority
- 12 of the primary cases have been dealt with quite some
- 13 time ago.
- 14 SIR BRIAN LANGSTAFF: But as far as the secondary cases
- 15 are concerned or, for that matter, the delayed primary
- 16 cases are concerned, there will be have been people
- 17 who are claiming today whose claims have not yet been
- 18 decided or determined, who will most probably have
- 19 suffered some financial loss, and that financial loss
- 20 will have been unrecompensed during the period that
- 21 they've been waiting for the assessment, will it?
- 22 A. I'm not sure. I'm not sure.
- 23 SIR BRIAN LANGSTAFF: So there's -- it's really allied to

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- 24 my question about settlement, is the question of
- 25 whether there is any way of, or any practice of

- 1 on the part of those who have made claims, that you're
- 2 aware of, or, broadly speaking, have those who have
- 3 participated made their claims to the tribunal been
- 4 content or accepting of the outcome?
- 5 Well, I think where there was any level of
- 6 dissatisfaction the award was appealed to
- 7 the High Court and, in the vast majority of cases,
- 8 that resulted in a significant uplink (sic) to
- q the award. And in some cases, in one or two cases, it
- 10 was actually appealed to the Supreme Court on a point
- 11 of law. So I think in terms of the amount there was
- 12 very little dissatisfaction. I think people genuinely
- 13 felt that this was fair and equitable compensation.
- 14 The dissatisfaction, where I've heard it expressed,
- 15 relates to the length of time that the process has
- 16 taken for some individuals.
- 17 Q. There is obviously no such thing as a typical case,
- 18 but is there a typical length of time that it's
- 19 taken -- for those who were directly infected, to the
- 20 primary cases, not the secondary cases, and who were
- 21 infected as adults, so if we leave aside
- 22 the additional complications in terms of time that
- 23 might arise in relation to children, if they were
- 24 making a claim in the late '90s or throughout the
- 25 2000s, and once it was extended to HIV, do you have
- 1 awarding anything on the interim, on the basis that
- 2 the claim must be worth at least this and we're only
- 3 really talking about the rest.
- 4 A. I'm aware of the interim payments made here,
- 5 Sir Brian, and I think that was greatly to be
- 6 welcomed, and I think if we were starting off again at
- 7 this point -- it's 20 years later, and our population
- 8 is 20 years older than they were when compensation was
- awarded in 2002 -- I'm sure we'd have gone for interim 9
- 10 payments initially as well, because there can be
- 11 a long prime before the final case is heard.
- 12 So I think our system has worked very well for our
- 13 members, but I think -- in looking at this, I think it
- 14 is wise to reflect on the potential for delay in
- 15 hearing individual cases.
- SIR BRIAN LANGSTAFF: So the system works well for 16
- 17 the reasons you've given, but it's not without the
- 18 opportunity to -- without the potential for
- 19 improvement?
- 20 A. Yes.
- COURT: Thank you. 21
- 22 MS RICHARDS: Brian, that anticipates what was going to be
- 23 my next question to you, which was: if you were
- 24 setting it up again, would there be any differences
- 25 that you would make? One you've just referred to was

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system.

1 the power to make interim payments. Are there any 2 other ways which, if you were starting from scratch 3 again, you would change what's been done, or ...?

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A. When we were starting from scratch, I mean, I have to say that, in the first instance, we were more in favour of ex gratia payments, because we were concerned about a very long complex system. Now, as it turned out, we were wrong. The individual assessment was better for members, the awards were better, and they got more closure afterwards.

If I was starting again, and it's 20 years later -- because bear in mind, this was 1995, it's 27 years later, and it's a much older population --I'd be very concerned about the age profile of the people claiming. So I think I'd be looking at a system where I'd be looking for significant interim payments, significant upfront payments, and then a fairly quick individual assessment if you're going down that road.

I think, as I said, the majority of cases were heard in, you know, a year to 18 months, and I think that should be the benchmark at -- no more than that. Q. I'm going to move now to a separate issue, which is the health amendment card and the Health Amendment

Act -- or the Health Amendment Card Act, I think it

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set up, and what you think swayed the Government and influenced the Government into setting up?

A. It was not a hard battle. Unlike the compensation battles, that was not a hard battle. I think the fact that you had a couple of hundred people with haemophilia; you had several hundred people who had been infected through blood transfusion; you had in excess of 1,000 women who had been infected through anti-D; all of these groups collectively wanted access to better healthcare.

So I think it was, very much, a case of coming up with a solution for, in a sense, in relation to the total population, a relatively small group of people, 3,000 or 4,000 people in total. So I think that's -- one of the reasons the card was put in place was because the number of people who would benefit would be finite and wouldn't be increasing. So it wasn't a hard battle to have it put in place.

Q. If we just look briefly at the Act, WITN7418005, please. If we go to page 3.

We've got the Health (Amendment) Act, 1996, and we can just pick up the essence of it in paragraph 2:

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"A health board shall make available without charge to persons who, in the opinion of the chief executive officer of the board, have contracted

1 is. Can you tell us first of all, in broad terms, how 2 the Irish healthcare system works and what a medical 3 card is?

4 A. Well, a medical card is a card which gives 5 an individual free access to public hospitals, to 6 general practitioners, and it's means based, so it's 7 typically if you have relatively low income or a lot 8 of dependants. Generally, in Ireland, if you don't --9 now, for haemophilia you have a separate card, called 10 a long-term illness card, which covers 11 the haemophilia-related costs such as factor 12 concentrates, ancillary supplies, they're all paid for 13 by the state. But for people in Ireland without 14 a medical card, then you pay for -- unlike the UK 15 National Health Service, you pay for your GPs visits, 16 you pay for your prescription drugs. And we have 17 a two-tier healthcare system: we have the public 18 hospitals, which are free for the vast majority of 19 the population, or you can also have private health 20 insurance. There are private hospitals or private

23 Q. Now, you've told us, in your statement, how the Health 24 Amendment Act Card came about. Can you just summarise 25 for us, what led to the campaign for that scheme to be

beds in public hospitals. So it's a mixed two-tier

hepatitis C directly or indirectly from the use of 2 Human Immunoglobulin-Anti-D or the receipt within the State of another blood product or a blood transfusion and to persons of such other classes (if any) as may 5 be prescribed ..."

> Then we have set out a number of services. Now, this is limited to hepatitis C. It doesn't encompass HIV?

It actually does, in the sense that, I mean, all of our members who were infected with HIV were also infected with hepatitis C. But it does cover -- I'm just looking at the specifics of the Act -- it does cover HIV as well, through blood and blood products. So if an individual had been infected with HIV through blood or blood products but had not been co-infected with hepatitis C, they would still get an HAA card.

17 Q. Then if we look at the guide you've appended to your 18 statement, WITN7418011, this is a 2020 piece of 19 guidance about the working of the card, and I think if 20 we can pick it up on page 3, under the heading 21 "Introduction":

> "This 2020 Information Guide to Services is for persons who contracted Hepatitis C through the administration within the State of contaminated blood and blood products and are currently eligible for a

1 Health (Amendment) Act (HAA) Card." 2 Then if we just look at the next paragraph: 3 "The new drug treatment for Hepatitis C has been 4 offered to all HAA card holders by the end of 2017 and 5 many cardholders have been successfully treated in the 6 last couple of years. 7 "The HAA card is a like time care ..." 8 So, is it right to understand that if an 9 individual has been successfully treated through the 10 new treatments and has cleared hepatitis C, they still have the HAA card for their lifetime? 11 12 A. Correct, because they will still have hepatitis C 13 antibodies. 14 Q. Then if we go down to the bottom of the page, under the heading "What is the HAA Card?": 15 16 "The ... Card is for eligible men, women and 17 children who contracted Hepatitis C from the 18 administration within the State of contaminated blood 19 or blood products. It is not the same as a medical 20 card [you've told us what that is], a GP visit 21 card ..." 22 What's that? 23 A. The Government have been extending free GP care to 24 different age groups. So you have -- so for people 25 over the age of 70, there's -- they can visit a GP 1 it would be unfair or amount to some form of queue 2 jumping because it was prioritising or conferring an 3 entitlement upon a particular group of individuals 4 that others would not have? 5 A. No. because the 3.500 individuals had developed 6 serious medical conditions as a result of medical 7 treatment already provided by the state, so you're 8 effectively giving additional and faster healthcare to 9 people who have already had their health impaired by 10 the actions of the state. Q. So it wasn't something that was -- has led to any 11 12 resentment or any sense of unfairness from the rest of 13 the population to your knowledge? 14 A. No, none whatsoever. 15 Q. Then you've set out in your statement, if we go back 16 to the statement, WITN7418001, and we go to page 33, 17 please, paragraph 77. 18 So you've set out in paragraph 77 the services that those who hold the HAA card receive, or are 19 20 entitled receive? A. Yes. 21

"Open Access to public hospital facilities for

Hepatitis C or any related condition. The cardholder

should not have to wait more than two weeks for an

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Q. The first is:

1 without payment. For children under the age of 6, 2 they can visit. So they have been kind of contracted 3 from both ends. 4 We're trying to get to a point of free GP visits 5 but it's going to take a number of years. So that's 6 a card that just gives you free GP visits. It doesn't 7 give you the prescriptions and other things. 8 Q. Then there is reference to a Drug Payment Scheme Card; 9 what's that? 10 A. That's if you have prescribed drugs there is a limit 11 you have to pay every month, and after that you get it reimbursed anything additional you pay. 12 13 Q. Then this guide goes on to explain that the: 14 "The HAA Card gives eligibility to additional HSE 15 services, on more flexible terms and conditions than 16 the medical card." 17 And then it explains it's for the lifetime of 18 the card holder, and it's personal to the card holder. 19 So it doesn't extend to family and members. But is 20 there an exception to that in relation to counselling 21 services? 22 A. Yes, the card is for the individual but family members 23 of a person who was infected with hep C or HIV can 24 avail of counselling under the card. 25 Q. Was there a concern when this scheme was enacted that 1 appointment with their liver specialist and also for 2 their first referral to another specialty. This is 3 generally referred to as the two-week rule." 4 Then if we go over the page: 5 "Once the cardholder is referred by the liver 6 consultant to another consultant in a public hospital 7 for the testing investigation or treatment of any 8 known or suspected condition related to Hepatitis C (or any condition which, while not related to 9 10 Hepatitis C, requires special treatment or care as a 11 result of the patient's infection with Hepatitis C), 12 they will be given priority appointment within two weeks for the first consultation." 13 14 And then: 15 "Subsequent appointments [you go on to say] with 16 17 of medical need ..." 18 19 20

a specialty outside hepatology [are done] on the basis

And there is no two-week rule applicable to that. So I just want to get a sense of how this works for the individual who has hepatitis C. This two-week rule, the entitlement to be seen within two weeks, in practice, at least prior to the pandemic, did that normally take place?

A. It did for a number of years. I would say it worked reasonably well until such time as the direct-acting

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anti-virals meant that the vast majority of people were able to clear hepatitis C infection.

Now, prior to that, you know, people with hepatitis C might have the need fairly urgently for a consultation with a dermatologist or a rheumatologist or a cardiologist, and this was designed that they weren't waiting in a long queue for that. So their hepatologist could say, "Okay, this individual, I want them to see a rheumatologist fairly quickly", so they'd get in within two weeks. It worked relatively well. But I think even before the pandemic, from, I'd say, maybe 2014, 2015, once the vast majority of people had been offered treatment for hepatitis C, it started to unravel somewhat. So that's one aspect of the cart that doesn't function very well, simply because of the pressure on the hospitals, on the pressure on the hospital beds. So I think also the requirement for people to see additional specialists outside of hepatology has diminished with successful treatment.

Q. Then if we continue through the list of services, soif we go further down the page, we've got:

"Access free of charge to a registered [GP] of [the individual's] choice and to all GP medical and surgical services for all medical conditions."

1 at home.

It works really well. We had a case in the last couple of weeks of one of our members who was being discharged from hospital, extremely sick, and within 24 hours we had 24-hour nursing care for him at home.

So, really, there is a clinical nurse coordinator who works for the HAA card scheme. She will assess this very quickly. The individual or the hospital will contact her or, if the individual contacts us, we will contact her. There is very good liaison between all of us so, really, we can get this in place very, very quickly.

13 Q. Then if we go over the page, we can see the list14 continuing:

"Access to chiropody and podiatry services ...

"Access to complementary therapies [and that includes] massage, reflexology, acupuncture, aromatherapy and hydrotherapy."

And they're all set out in the guide that we looked at a few minutes ago, and then:

"Access to counselling services for the affected individual."

And then we see they're also available to relatives or carers.

What's the role, in relation to all of these

And you've explained how that is different from the position of the ordinary medical card holder. Top of the next page there is an entitlement to all necessary routine and emergency dental treatment.

Then paragraph (d), free hearing tests and hearing aids and entitlement to an eye examination, spectacles, contact lenses and so on.

Then:

"Certain aids and appliance ..."

10 And you've given some examples there, walking 11 sticks, frames, wheelchairs, et cetera:

"Access to physiotherapy when prescribed ..."

And then:

"A home nursing service ... available in respect of all conditions affecting the health of eligible people."

How does that work and how much recourse to it have those who hold the cards had to have, do you know?

A. I think most card holders have not had to have
 recourse to that, but when they have it's very, very
 significant, in some cases 24-hour nursing care. So
 we've had a number of members where, certainly when
 they were extremely seriously ill, perhaps near the
 end of life, that they will get 24-hour nursing care

1 services, of the liaison officer?

A. It's crucial. You've got about 3,500 cards issued in a population of 5 million. You know, most GPs won't have seen the card, a lot of pharmacists won't be familiar with the card, so the role of liaison officer is to ensure that individual gets the services which they should be getting.

I would say their role has been really important. There are 10 of them, they cover geographic areas, so each individual who has a card will have an assigned liaison officer, so if they have any difficulty getting access to any of the services, they contact the liaison officer and their job is to sort it out pretty quickly. In some cases the individual will contact us. Most weeks we're dealing with at least one query from a member about something to do with the HAA card. And they're usually in the grey areas where this may or may not be covered.

And I have to say that we've found the liaison officers to be extremely good to work with, they cut through a lot of the bureaucracy. I would say that the scheme has been extremely successful. It would not have been successful if we didn't have the liaison officers.

25 Q. Then if we just go to the next paragraph. We can see,

to

- 1 here, the reference to home support services.
- 2 **A.** Yes.
- 3 Q. Now, as I understand it, this is something that's
- 4 distinct from the home nursing service?
- 5 A. Correct.
- 6 Q. That's meeting clinical needs, care provided by, or
- 7 arranged by nurses?
- 8 A. Correct.
- 9 Q. This is more along the lines of domiciliary support,
- 10 assistance within the home with household tasks; is
- 11 that right?
- 12 A. Yes.
- 13 Q. And, again, what's the take-up and importance been of
- 14 that particular service?
- 15 A. There has been a significant take-up of that.
- 16 A significant number of our members, certainly, would
- 17 have a home worker who comes in and does tasks around
- the house: cleaning, cooking, ironing, gardening.
- 19 They would receive a defined number of days per week.
- 20 They can either -- the Health Service will employ
- a home worker centrally and assign them, if they wish,
- or, if they wish, they can employ them themselves and
- 23 be reimbursed for the costs of that. Because --
- 24 the latter is necessary because of confidentiality.
- 25 I think confidentiality permeates everything in
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- 1 If you were setting up the scheme again from scratch,
- 2 would you make any changes to it or has it worked in
- 3 the way you would have wished it to?
- 4 A. No, I think I wouldn't make any changes, I think it
- 5 works very well. I would clarify, perhaps,
- 6 the two-week rule, and just, you know, include it if
- 7 it's going to work and don't include it if it's not
- 8 going to work.
- 9 SIR BRIAN LANGSTAFF: That leaves the question of how
- 10 long, doesn't it? It leaves the question of how long.
- 11 **A.** How long?
- 12 SIR BRIAN LANGSTAFF: How long one may have to wait for
- 13 the various things that would be covered by
- 14 the two-week rule. Because if you don't have a period
- of time, you've no yardstick to judge the length of
- 16 delay.
- 17 A. But in fairness, there has been a degree of pragmatism
- in the way that this is operated by the liaison
- 19 officers. So I'm aware of cases among our members
- 20 where they need to see a specialist in a particular
- area they're concerned about, they will go privately,
- even though the card doesn't pay for that, and
- the card has actually paid for that. So there are
- 24 cases where, if you can make a case that an individual
- 25 needs to see a specialist within a short period of

- 1 relation to hepatitis C and that card. People are
- 2 very concerned about maintaining their
- 3 confidentiality, so in some cases that has meant that
 - they will employ somebody locally, themselves, and
- 5 then the costs will be reimbursed by the Health
- 6 Service.

- 7 Q. Now, you were asked in your statement whether you
- 8 thought the HAA card was a success and you've said
- 9 unequivocally yes. Why is that? Why is that your
- 10 view?
- 11 A. I would have said if we were speaking back in '95,
- 12 '96, '97, our members were much more concerned about
- 13 compensation on these issues and the forthcoming
- inquiry than they were about the HAA card. But when
- 15 I look back on it now with the benefit of hindsight,
- 16 the HAA card has been absolutely crucial because it
- 17 gives people prioritised access to a lot of
- the healthcare and services and support they need on
- 19 an ongoing basis. It has been invaluable for people
- when they run into trouble health-wise. And when
- 21 people are at the point where -- if they are getting
- 22 near to the end of their life, it has been absolutely
- 23 amazing in terms of the help and support we can put in
- 24 place very quickly.
- 25 Q. And same question as with the compensation tribunal.

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- 1 time and they have to pay for that, then they can seek
- 2 reimbursement. And in many cases there is
- 3 reimbursement.

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- 4 SIR BRIAN LANGSTAFF: Without the two-week rule that would
 - not be easy to achieve, I imagine.
- 6 A. No, I think it's -- perhaps, perhaps not. I think the
- 7 two-week rule is, you know, well intentioned. It just
- 8 hasn't worked for the last number of years because of
- 9 the overwhelming pressure on the Health Service.
- 10 SIR BRIAN LANGSTAFF: I can see that in some societies it
- 11 may be aspirational rather than realistic but the
- issue may be finding the right number of weeks to
 - represent the balance.
- 14 A. Yes, and you'd also, perhaps, run into the problem
- where some consultants will resent being told that you
- 16 need to see a particular patient -- a group of
- 17 patients within two weeks, when they have a long
- waiting list. I've never met a consultant who resents
- being paid, so that removes the problem.
- 20 SIR BRIAN LANGSTAFF: Yes.
- 21 MS RICHARDS: Sir, I note the time. I've probably only
 - got about another 10, 15 minutes of questions, because
- 23 there is really just one further topic I want to
- 24 cover, which is that of insurance. So we could either
- 25 continue now, or take a break and come back after the

break

SIR BRIAN LANGSTAFF: Well, it may be more sensible to continue. Let me explain and ask Brian what he would prefer to do.

Normally at this stage we would have a break of about half an hour so that people can have a coffee, and in particular for those who are listening to give them a chance to have a break, bearing in mind the effects or lingering effects of some of the conditions which some of them may have.

But the general practice is, after counsel has finished the questions from the Inquiry, there is an opportunity, it's prescribed by law, for those who are represented by legal representatives, to have those legal representatives suggest to counsel questions which it is appropriate should be asked, and that process needs a bit of time, obviously, because they haven't yet heard what you had to say in answer to the earlier questions.

So if we go on for 15 minutes now, there will be a break of perhaps longer than half an hour, and then there will be the last session for today. You'll be finished, I would suspect probably by lunchtime, but I can't tell you how long because it depends how many questions there will be and there may be quite

becomes from very difficult to impossible.

So, really, people were in the situation where they couldn't get life insurance, they couldn't get mortgage insurance, which in some cases meant they couldn't buy a house. So this issue was in the back of our minds at all times. So when we were discussing all of the issues in the two years and three months it took us to agree the terms of reference for the Lindsay Inquiry, we discussed all sorts of issues, this was one of the issues that we kept raising: insurance, mortgage insurance, life insurance, mortgage insurance.

And then around the time of the 2002 Act we again raised the issue. So the Government agreed that they would set up a Steering Group with the organisations representing those who had been affected. We had our legal teams with the Department to try and see if they could come up with a scheme. And that took -- it took at least four years to get that up and running. And that culminated in the 2006 Act.

- Q. And so we have the Hepatitis C Compensation Tribunal
 (Amendment) Act 2006, which set up the scheme. And
 I think we've got some regulations?
- **A.** Yes.
- 25 Q. But I don't think we need to look at those.

a number. The alternative is breaking, 15 minutes
 break, for half an hour or so --

3 A. No, please, proceed.

SIR BRIAN LANGSTAFF: I think we're still within the
 period of time that's acceptable to the stenographers,
 who also have been borne in mind. Let's proceed.

MS RICHARDS: Absolutely.

So the third area I wanted to ask you about in terms of the state's response in Ireland, Brian, is in relation to insurance. In 2006 something called the Hepatitis C Insurance Scheme was set up. What led to that being set up at that point in time?

A. Well, if I go right back to 1986, we first raised concerns about the inability of people with haemophilia, with hep C -- or with HIV, at the time, to get life insurance or mortgage insurance. We actually had a meeting with a Government minister in 1987 and, as you saw on the "AIDS, Haemophilia and the Government" booklet, we put this in our list of issues for the Government in 1988, and they didn't deal with that at the time they set up the HHT. So we were always conscious that even before HIV and hepatitis C, it was difficult for people with haemophilia to get life insurance or mortgage insurance without

a loading. Once you add in HIV and/or hepatitis C, it

If we go back to that guide that we were looking at earlier, because it's got a section on insurance, and think it might be a convenient way of picking it up.

WITN7418011, please, page 23.

So we've got the heading "Insurance Scheme", travel insurance, mortgage protection insurance, life insurance for persons who were infected through blood or blood products within the state.

Then we've got the general rules for the insurance scheme, and if we just look at the whole page for a moment, we can see there is a heading at the bottom half of the page:

"Eligibility.

"To avail of the insurance scheme you must have an eligibility certificate."

Then there is a description of how you get that.

Then, in terms of getting an eligibility
certificate, if you've got an HAA card or you've been
awarded compensation by the tribunal, you get
the eligibility certificate automatically?

22 A. Correct, yes.

Q. If you don't fall within either of those categories,
I don't know if there are any who would, you then have
to make out a case for eligibility?

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A. Yes.

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- 2 Q. But essentially it's proof of infection or acceptance 3 that you were infected and infected through blood or 4 blood products?
- 5 A. Yes, but you don't have to keep proving it. So as you 6 say, if you have an HAA card or if you got an award 7 from the Compensation Tribunal, as a person with hep C 8 or HIV then you can take out the insurance.
- 9 Q. Then if we just go back to the top half of the page, 10 so we can see the three types of insurance under the 11 scheme, so: life insurance, mortgage protection and 12 travel insurance.

Can I deal with life insurance first of all. How does that work in practice? What does this give people that they would otherwise have struggled to get?

A. As I said, somebody with haemophilia, without HIV or hepatitis C, is often loaded for life insurance. If you have hepatitis C, if you can get life insurance you will be severely loaded. If you have hepatitis C and HIV, you will be deemed to be uninsurable, you won't get life insurance.

Now, the scheme, first of all, you can take out life insurance up to your 65th birthday. But if you took it out in the first year of the scheme, we'd

- 1 insurance attainable for people.
- 2 Q. Is this underwritten by the state?
- 3 A. Yes. And in fact the -- so what happens is, we have 4 two insurance companies who provide policies under 5 the scheme. They have to be accepted by the scheme. 6 And then the insurance company will -- you know, 7 they'll do an evaluation, as they normally do, and 8 then they will quote a premium, and the premium --9 there is a premium quoted to the individual, but then

So, for example, with somebody who has hepatitis C, the premium to the individual is the premium for a perfectly healthy person. The premium -- there is an additional premium then to be paid by the insurance scheme on behalf of the Government.

there is also a premium quoted to the Government.

If the individual is co-infected and is deemed to be uninsurable, effectively the Government becomes the re-insurer. So they'll still look at the policy from the insurance company, they'll still pay the same premium as a perfectly healthy person, but in effect there is an arrangement between the Government and the insurance company about who pays if and when the person passes away.

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25 Just sticking with life insurance for a moment, how Q.

birthday. So in fact for the first year after the implementation of the scheme I was like an insurance salesman trying to get as many of our members to take it out as possible, because you got an extra ten years of cover. And also, if you took it out after the

negotiate that you could be insured up to your 75th

first year, if you were under the age of 30 or over the age of 50, there was one or two years until you 9 got full cover. So it was -- really, the optimum time 10 to take out the insurance was in the first year of the 11 scheme.

> What it covers is, you will basically get life insurance up to I think it's seven times the average income or up to a maximum of about EUR 525,000. You will be able to take out life insurance at the same premium for a person of your age who is perfectly healthy, who doesn't have HIV, who doesn't have hepatitis C, who doesn't have haemophilia. The only difference is if you're a smoker. They actually -they load that along the board.

So if you've got a 50-year-old man with co-infection, with haemophilia, with joint arthropathy, with kidney disease, with liver disease, he will get insurance at the same rate as a perfectly healthy 50-year old. So it makes

- 1 important has that been for your members?
- 2 A. I think it's been very important because it means that
- 3 individuals can take out life insurance at
- 4 a reasonable cost; they can provide for their family,
- 5 their dependants, in the event of their death up to
- 6 the age of 65 or 75, depending on when they took it
- 7 out; and it also means that if they do get
- 8 compensation they can actually use that compensation
- to live their life and not necessarily have to salt it 9
- 10 to away to provide for their family in the event of
- 11 their death.
- 12 Q. Then the second type of insurance, the mortgage
- 13 protection insurance for a new primary home or repair,
- 14 renovation or refurbishment of current primary home;
- 15 does that, essentially, work in the same way?
- 16 A. Yes.
- 17 Q. But you've told is in your statement that the uptake
- 18 of that has been relatively low. Do you know why that
- 19 was?
- I think there was a reasonable uptake in year 1 but 20 A.
- 21 after that, it just -- people just haven't been taking
- 22 it up. I'm not sure why. It's surprising. To me,
- 23 also, with the life insurance, I would have thought
- 24 that practically every person, you know, with Hep C or
- HIV, would take out life insurance under the scheme in 25

year 1 and a lot chose not to.

So the mortgage protection insurance was -the uptake has been quite slow or low. Also, in
year 1 of the scheme there was a remortgage, so you
could actually take out additional insurance for
100,000 if you had an existing mortgage. Again, there
was very little take-up on that.

- 8 Q. Then the third form of insurance is travel insurance.
- 9 Again, is that essentially done in the same way, so
- 10 you're insured in the way you would be if you were
- 11 in --

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- 12 A. Perfect health.
- 13 Q. -- perfect health, and then the increase is
- 14 effectively underwritten or paid for by the state?
- 15 **A.** Yes.

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- 16 Q. And how important has that been for --
- 17 A. Extremely important, I think the vast majority of card
- holders take that out, especially now we've started
- 19 travelling again post-Covid, but it's really
- 20 important. It means that the individual and their
- 21 family can take out travel insurance. That's been
- very, very useful and it gives them low-cost travel
- 23 insurance. And I get queries all of the time from
- 24 people with haemophilia who don't have HIV or
- 25 hepatitis C who are concerned because they find it

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back about 2012, to come back on the board, he made me promise he'd never have to go to an insurance meeting again.

So it was -- it was a lot of work to put this one in place, simply because of the -- it was a novel concept. I don't think it had been done before. And the insurance industry are, you know, they're very conservative in the way they look at things, so it look a lot of work to put it in place.

- 10 Q. Then just a final question from me for now, Brian.
- 11 Those three types of scheme that we've been looking
- 12 at, so the provision for compensation through
- the tribunal, the HAA card and then the insurance
- 14 scheme, these are all measures that have been taken by
- 15 the state --
- 16 A. Yes.
- 17 Q. -- in recognition, would this be right to say, of
- 18 the suffering and disadvantage that individuals have
- 19 experienced through treatment at the hands of
- 20 the state. As well as the obvious benefits of
- 21 the schemes themselves, the provision of financial
- 22 assistance, access to health services and so on, how
- 23 important has it been for those who were infected in
- 24 Ireland to -- that very fact of state recognition that
- 25 something had to be done?

1 expensive to get travel insurance. So, ironically, if

2 you're in Ireland and you have HIV or hepatitis C,

- 3 it's easier to get travel insurance, life insurance or
- 4 mortgage insurance than if you just have haemophilia.
- 5 Q. You told us how this was something raised back in
- 6 the '80s and it took all of the way through the
- 7 discussions following the 2002 Act and the Lindsay
- 8 Inquiry report for this to eventually come to
- 9 fruition. Was there resistance on the part of
- 10 Government or was it just ignored or ...?
- 11 A. There was a little bit of resistance initially, but,
- 12 again, as the personal stories come out from Lindsay,
- as the public awareness increased -- and Government
- 14 were genuinely sympathetic and their response was
- sympathetic, so there was a willingness to explore
- this, but from a practical point of view it was still
- 17 quite difficult to put it in place, so we had -- you
- 18 know, we had four legal teams, we had a team of
- 19 actuaries, we had a couple of insurance specialists
- and brokers, we had the Department of Health, we had
- 21 the four organisations. I think we had
- 22 35 excruciatingly long steering committee meetings
- over those four years. I know my colleague -- or
- former chairman, who was at those meetings with me,
- 25 when he left the Society board later and I asked him

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- A. I think hugely important. When I look at the Lindsay
- 2 Inquiry and I think a couple of things come to mind.
- 3 The personal testimony was hugely important.
- 4 The public understanding of what had happened to
- 5 the community was very, very important, and the public
- 6 understanding was, frankly, helped by very responsible
- 7 media coverage in the Irish media. All of the main
- 8 daily newspapers covered it, you know, in great
- 9 detail.

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I think the apology from the Government after thereport came out, the compensation which was put in

- 12 place without having to wait for the Inquiry report,
- the HAA card, the insurance, the tax concessions,
- these were all really important in an overall view
- that: look, this happened, this was an awful thing
- tiat. look, tills happened, tills was all awiti tilling
- that happened to you, we're really sorry and we're
- going to make it up to you in any way that we can.
- 18 MS RICHARDS: Thank you.

Sir, those are the questions I have for Brian.

But if we could now take our break and afford the opportunity to the Core Participants to suggest

- further matters they might want me to ask.

 SIR BRIAN LANGSTAFF: How long a break do you think you
- 25 **MS RICHARDS:** Well, I think probably our normal half an

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1	hour break should suffice because a lot of		
2	the questions I have asked have reflected		
3	the suggestions already made to me, so if we take half		
4	an hour.		
5	SIR BRIAN LANGSTAFF: What I'll say in these circumstances		
6	is my usual. We will take a break and come back not		
7	before 12.00. It may be later; if so, we'll let you		
8	know, but otherwise not before 12.00.		
9	MS RICHARDS: And, sir, the normal advice to the witness.		
10	(11.32 am)		
11	(A short break)		
12	(12.00 pm)		
13	(Proceedings delayed)		

14 (12.11 pm)

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MS RICHARDS: Brian, just a handful of further questions.
 The first is about the HAA card. Does it have any implications in terms of accessing liver transplants?

A. No. The -- no. The short answer is no. Liver transplants are assessed on a clinical need. If a person with haemophilia requires a liver transplant they go on the waiting list in the same way as everybody else.

I guess where it does make a difference is, we've had quite a number of members who have had to have liver transplants in Ireland. We had a couple of

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dealt with vast majority of cases of carers, so he would have all of the detail.

Q. Thank you.

In terms of the information that's publicly available about the tribunal's approach, does the Government publish data about the awards?

A. The tribunal publishes an annual report and they publish the total number of cases heard and then the -- the -- sort of, the total awards, and you can divide one by the other and get the average or mean amount. But in a sense that's fairly meaningless because, you know, you might have a case of, you know, somebody who has got hepatitis C and HIV co-infection and has had serious clinical and social consequences or somebody who is perhaps a hepatitis C antibody positive, was never virus positive, so all of the cases are put in together, they don't break it down in tranches, so ...

But they do publish an annual report and the annual report gives the breakdown of the total number of cases. And I think if you look at the annual report, the last annual report that was published, I think for 2020, I think there were about 3,500 cases heard. The average award including the reparation payment was about a quarter of a million

1 members who had liver transplants in the UK because if

2 they're co-co-infected with HIV then they go to

a specialist unit in the UK, because the numbers in

4 the Republic of Ireland would be so small that the

5 specialist aftercare would be better in one centre.

6 So the card will provide extra help and support to the

7 individual when they're going over. So, for example,

8 you know, on one or two occasions I've come over to

9 the UK with a member when they were being assessed for

a liver transplant and the card would pay the costs of

11 that visit over.

12 Q. Then does the HAA card cover the joint operations for

13 haemophiliacs?

14 A. No, that's entirely under the Haemophilia Service.

15 Q. The home care that you described, what's the source of

funding for that? Is that the Department of Health?

17 A. The Department of Health.

18 Q. I asked you earlier about how the tribunal approaches

19 the assessment of the cost of care, if carers are

20 making a claim, and you indicated you weren't sure of

21 how they approached it?

22 A. Yes

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23 Q. Is there a way we would be able to find that out?

24 A. Absolutely. I think if you were to contact

25 Raymond Bradley from Malcomson Law, he would have

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Euros, and the average award which had been appealed was about half a million Euros.

3 Q. You gave some figures that are quoted in

4 the Archer Inquiry Report about both the range and

average. Are those still accurate, do you know, or

6 has there been a significant change since then?

7 A. Can you remind me what figures I quoted for Archer.

8 Q. I can. I haven't got the report in front of me, but

9 the final report says that you told the Archer Inquiry

the average payment was -- it's about EUR 850,000,

11 from a range of between EUR 14,000 and

12 EUR 3.1 million.

13 A. That range would certainly be correct. It is

14 impossible to know what the average payment was to

a person with haemophilia, but it would certainly be

higher than the average payment for the tribunal

awards generally because, as I say, they cover an

18 entire range of cases from primary claimants, to

19 secondary claimants, to carers, so I would think

20 that's -- I think that's reasonable.

21 Q. And in terms of the tribunal awards, is it right to

22 understand then that the individual awards are not

23 published? There is no --

24 A. That's correct.

25 Q. There is no decision from the Tribunal?

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- Α. That's correct. 1
- 2 Q. If they are appealed to the High Court, the High Court
- 3 judgments would be publicly available?
- 4 A. Not that I'm aware of, no.
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- 6 A. Again, I think right through every step of this
- 7 process we've taken as much care as possible to ensure
- 8 confidentiality.
- 9 Q. Yes, understood.
- 10 Just turning back to the HAA card scheme. The
- 11 liaison officers, what's the background of
- 12 the officers?
- 13 A. They would generally be health service employees.
- 14 They would be -- perhaps some of them would have
- 15 a nursing background but generally they'd be health
- 16 service employees. But crucially, when they started
- 17 in that role, when the card was established, we did
- 18 some training for them, as did the other
- 19 organisations. So they came around to the
- 20 Irish Haemophilia Society, to the Transfusion Positive
- 21 Group, to the Anti-D support group. They heard about
- 22 the issues, they met the community. So they gained an
- 23 understanding of the areas they were going to be
- 24 dealing with.

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25 Q. Then a much broader question next. Following the

- the tenders and procurement for the haemophilia

Selection Monitoring Advisory Board, which carries out

- 3 treatments. And I think that's now been running since
- 4 2002 and in that period of time our availability of
- 5 treatment has remarkably improved in terms of both
- 6 quantity and quality. I think we're the first country
- 7 in the world to switch every patient with haemophilia 8
 - to extended half-life factor concentrates, one of the
- 9 first to make the new subcutaneous treatments
 - available across the board to everybody who wanted it,
- 11 and, crucially, that's been done in a way where
- 12 the patient organisation and the doctors are formally
- 13 involved in the decision.
- 14 And ironically, despite the fears of the
- 15 Department of Health when this was agreed, it has
- 16 actually turned out to be cost effective. It has
- 17 saved them a lot of money because we've made it much
- 18 more competitive and efficient and effective than it
- 19 had been here before.
- 20 Q. Just --
- 21 A. Sorry, just again to expand, I mean I think
- 22 the culture has changed. I think everybody realised
- 23 that this can't be allowed to happen again, so, you
- 24 know, there is a co-designed approach to the
- Haemophilia Service, major decisions were taken in 25

1 publication of the Lindsay Tribunal report, has that 2 had any broader effect in terms of culture change in

3 Ireland in terms of the approach to treatment and

- 4 patient safety?
- 5 A. Absolutely. I think when you look at
- 6 the recommendations from the Lindsay Inquiry, which
- 7 were fairly broad, talking about the need for
- 8 a committee to look at blood products, and doctors and
- 9 patients to work more closely, I think we put a lot of
- 10 work before the end of the Lindsay Inquiry into
- 11 recommendations for the future and a lot of those have
- 12 come to pass. So you had the establishment of
- 13 a statutory National Haemophilia Council, which brings
- 14 together the four haemophilia treatment centres,
- 15 the Irish Haemophilia Society, the Health Service, the
- 16 Department of Health and a couple of key experts.
- 17 And crucially that Council recommends policy to 18 the Minister, but really sets priorities for the year
- 19 for the whole service. And it's really led to
- 20 a position where we now have a co-designed service
- 21 where the Society are involved in all of the major
- 22 decisions in relation to the implementation of the
- 23 haemophilia care service in the country.
- 24 Secondly, we had the establishment on

a non-statutory basis of the Haemophilia Product

- 1 consultation with the patient organisation, and
- 2 especially now, as we're entering an era of, you know,
- 3 therapeutic choices, new therapies, new types of
- 4 therapies, gene therapy, where you absolutely have to
- 5 have shared decision-making, so I think the culture
- 6 has been changing, has changed, and I think will have
- 7 to evolve even more in the future.
- 8 Q. Do you have any sense of the extent to which that
- 9 culture change has extended beyond the haemophilia
- 10 community? For example, the other bodies,
- 11 organisations you mentioned, those involved with
- 12 the -- advocating on behalf of those who were infected
- 13 through transfusion or infected through anti-D, would
- 14 they, do you know, report a similar shift in terms of
- 15 culture and patient involvement and shared
- 16 decision-making?

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- 17 A. No. Not at all. And, in fact, quite sadly, I think
- 18 the organisation which represented the women infected
- 19 through anti-D imploded. The transfusion group have
- 20 just -- they really have just concentrated on
- 21 the issues around the card and on compensation but 22 they haven't got involved in any sense in terms of
- 23 policy.
- 24 But, of course, haemophilia is different. If you

had a blood transfusion, you had an underlying

condition which could be anything. With haemophilia 1 2 and bleeding disorders there was a core set of the 3 same treatments, the same ideals, that go right 4 through that. So -- but I think none of the other 5 organisations have been involved in policy in that 6 sense, although we do have a statutory hepatitis C 7 consultative council which does include 8 the organisations whose members were affected, and we 9 sit with the Department of Health and we monitor the 10 implementation of the HAA card and also the council 11 would organise information days every couple of years.

12 Then just going back to the work of the Compensation Q. 13 Tribunal. Do you know what approach is taken to 14 the assessment of compensation if there is a dispute 15 between family members? So there may have been --16 there may be competing claims in terms of care or 17 dependency. Do you know whether that's arisen at all 18 in the Tribunal?

19 A. I can't really answer that. I think, again, you could 20 talk to our legal team and they'd be able to clarify 21 that for you, but I know that, I mean, there have been 22 cases where several family members have been granted 23 awards for taking care of a person at different points 24 in time.

25 Then the awards made by the Tribunal, are they taken

the World Federation and the European Consortium.

Do you know to what extent the measures that you've been describing in Ireland, in particular in relation to the insurance scheme and the HAA card, whether those are schemes or measures that have been set up in other countries?

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

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8 MS RICHARDS: Sir, those are the questions I'm proposing 9 to ask from those that have been suggested to me by 10 the Core Participants.

Do you have any further questions for Brian?

SIR BRIAN LANGSTAFF: Yes, a couple of areas, if I may.

Am I right in thinking that since the early 2000s, personal injury claims, except for those that arise out of medical negligence, alleged medical negligence, have been determined not in the courts, as they used to be, but by a compensation, or a tribunal, a PIAB, the Personal Injury Assessment Board?

18 19 A. I think that's an option for people with personal 20 injuries. I think it's an option that they can go to 21 the PIAB but they can also take legal action and go to 22 the court. I'm not fully aware of it but think it's 23 an option that they have. They don't have to go to 24 the PIAB.

25 SIR BRIAN LANGSTAFF: When they do go to the PIAB, to what

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1 into account for the purposes of any applications for 2 welfare benefits?

3 A. No, they're not, they're specifically excluded. And 4 in fact, because of the arrangements we've made with 5 the Revenue Confidential Service, they can't even know 6 about them.

7 Q. And in relation to taxation, you've explained 8 the position in your statement, but for the benefit of 9 those who may not have been able to read through your 10 statement, what in short is the position in terms of 11 taxation and the compensation awards?

12 The compensation awards are tax-free. That's clear. A.

13 But we also made submissions to the Revenue that there 14 is a section 189 in the Taxes Consolidation Act which 15 states that if an individual is permanently and

16 totally incapacitated then the income arising from 17 the award can also be tax exempt or exempt from

18 capital gains tax. And we made a submission which was 19 accepted that, in fact, every person with haemophilia

20 who got hepatitis C or HIV would fall under

21 section 189, so their awards are tax-free but also any 22 income or capital gains earned from the awards, income

23 from the awards, is also tax-free.

24 Q. And then last question arises from your involvement 25 internationally, you've been involved both in terms of

1 extent does the process there differ, if at all, from 2 the process that you're describing in the compensation 3 tribunal specifically for HCV and HIV?

4 A. I have no experience or exposure to the PIAB so 5 I can't answer that question, Sir Brian, but I would 6 say that the Compensation Tribunal was much more like 7 a court hearing to assess damages. I'm not sure 8 the PIAB is the same.

SIR BRIAN LANGSTAFF: All right. It was essentially that, 9 10 that I was just trying to get a sense of how similar 11 the process is in terms of compensating those who have 12 suffered infection through the action of the state --

13 Mm-hmm.

14 SIR BRIAN LANGSTAFF: -- in respect of their haemophilia 15 treatment or their transfusions, with the process that 16 would be applied in the courts.

The next question you may not be able to answer, 17 18 but I'm given to understand that there may be moves in 19 Ireland, in the Dáil, to introduce legislation which 20 will effectively reduce the amount of money which is 21 paid out in terms of compensation payments for those 22 who succeed in claims. Do you have any awareness of 23 that or can you enlighten me on that?

24 A. No, I think that the vast -- in terms of 25 the Hepatitis C Compensation Tribunal, the vast 88

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1	majority of the claims have been dealt with at this	1	able to get to the questions asked that they wanted,
2	point in time. I think the vast proportion of	2	they wouldn't accept witnesses. So it became very
3	the expenditure has already been spent. I'm not aware	3	clear to us that the Finlay Tribunal was purely
4	of any push by Government to limit the amount	4	limited in its scope and we decided to withdraw from
5	of funding being made available to the tribunal. If	5	that.
6	that was the case we would wholeheartedly oppose that.	6	And then we had a further two-year and three-m
7	SIR BRIAN LANGSTAFF: It really arises out of your	7	period where we spent that time negotiating with the
8	evidence that, in effect, there is no benchmarking of	8	Government to establish the Lindsay Tribunal.
9	awards in this area. It's all a question of what	9	I think the reason it was established was because
10	the Tribunal feels is appropriate, subject to appeal?	10	first of all, we kept the pressure up, we kept
11	A. Yes.	11	demanding a new Inquiry which specifically would lo
12	SIR BRIAN LANGSTAFF: The second area which I wanted to	12	at haemophilia. The discussions on the Terms of
13	ask you about was just this, curiosity really.	13	Reference took a long, long time. They took longer
14	You described how the hepatitis C problems were	14	than the Inquiry, you know, two years and
15	sorted by legislation well before the Lindsay Tribunal	15	three months.
16	was established. What was it, do you think, that	16	Having said that, during the course of those
17	persuaded Government to set up the Lindsay Tribunal?	17	discussions we got Government agreement to the
18	A. Well, the Lindsay Tribunal was set up	18	provision of recombinant factor concentrates for
19	the Government established the Finlay Tribunal	19	everybody. We got Government agreement to the for
20	in 1997, and that was meant to look at the infection	20	for a new national haemophilia treatment centre. Bu
21	of people with hepatitis C through anti-D blood	21	I think there was a lot of discussion on the terms of
22	transfusion and blood products.	22	reference. Which, in the end, probably worked well
23	Unfortunately, it became [technical issues -	23	because it did define it very, very clearly. But,
24	audio drop] on blood transfusion and they were not	24	I mean, I think the Government were not keen on ha
25	focusing on haemophilia issues, our legal team was not 89	25	a second Inquiry, but we were not keen and we woul 90
1	not accept the first Inquiry, where it clearly and	1	crucially important, not just in terms of looking at

patently was not going to deal with our issues. SIR BRIAN LANGSTAFF: Thank you.

The other matter is this: you mentioned that the Haemophilia Society of Ireland had made a number of recommendations on the back of the Lindsay Tribunal.

7 A.

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SIR BRIAN LANGSTAFF: And most of those or some of those 8 9 have been put into effect. What are you most disappointed was not put into effect? 10

A. I can't think of any recommendation that we made that 11 12 we regret not being put into effect. There really 13 wasn't -- I mean, I think all of our major 14 recommendations have been implemented and accepted.

SIR BRIAN LANGSTAFF: And which of those do you think has 15 16 been perhaps the most significant?

17 A. The formal role for the patient organisation and 18 the doctors in decision-making, learning from the past 19 where decisions were taken on financial grounds would 20 not be acceptable. So I think the formal role for the 21 Haemophilia Society and the doctors in the choice of 22 treatments on the tender board, the formal 23 establishment of a statutory haemophilia council, 24 which brings together the Ministry of Health,

the doctors and the Society -- and that's actually

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year and three-month gotiating with the y Tribunal. shed was because, we kept

cifically would look the Terms of hey took longer rs and

urse of those reement to the centrates for reement to the funding tment centre. But on the terms of ably worked well early. But, e not keen on having een and we would

of looking at recommendations and priorities but it means six times per year, at least, we sit down with the Health Ministry, with the doctors, to discuss haemophilia policy and, in fact, the Council meets in our office. That's been really important.

And I think the funding for the Irish Haemophilia Society was really important. We were funded prior to the Lindsay Tribunal. We got our first funding from the Government back in 1989, after the first recompense campaign, and we're now at the point where the Irish Haemophilia Society, about 75 per cent of our funding comes from the Government. That's really -- it really allows us to do the work that we do very, very well.

It also means, frankly, the Government see the advantage of this because in terms of the procurement process for medications and factor concentrates we will always insist on having the safest and most efficacious treatments.

We carried out a full economic assessment in 2018 of our work on that board since 2002 and we have saved them EUR 175 million. In that point, in that entire period of time, they had given us grants of about EUR 6 million. So they gave us grants of 6 million, we

1	saved them 175 million. So I think the Government at	1	US companies to see if they would give a contribution
2	this point accepts that it definitely makes sense as	2	to any eventual Irish compensation scheme. My
3	well to continue that.	3	understanding is that they were unsuccessful in that
4	SIR BRIAN LANGSTAFF: I don't know if there are questions	4	attempt.
5	which arise out of that.	5	Now, we did assist our members a number of ou
6	MS RICHARDS: There are not, but I have one further issue	6	members in taking legal against some of the US pharm
7	I've been asked to raise with you, Brian.	7	companies and some of them did receive an award
8	Do you know whether the Irish Government had any	8	separately.
9	discussions with the pharmaceutical industry pharma	9	Q. Thank you.
10	companies who had supplied concentrates that had	10	MS RICHARDS: Sir, that's it for my questions.
11	caused infection at any time, in terms of trying to	11	Brian, is there anything that you would wish to
12	secure a contribution by pharma to the funding of	12	add?
13	the compensation schemes?	13	A. Yes. Preparing the statement was a lot of work but
14	A. When we started our legal cases back in 1989, 1990	14	that was easy. I found when I got the section 9
15	and these were proceeding very, very slowly then,	15	letter, I found it opened up a lot of issues for me.
16	I mentioned earlier that at the end of 1990 we started	16	You know, I found it difficult emotionally,
17	a political and media campaign to get the Ministry of	17	personally. I was seeing names, faces, scenarios,
18	Health to agree compensation, and, you know, again,	18	events coming back into my head from the last 20, 30,
19	there was a total lack of response from the Government	19	40 years. And I think Seamus Heaney said that once
20	for several months, culminating at a point when,	20	in a lifetime the longed for tidal wave of justice can
21	actually, an offer was made on the same evening that	21	rise up and hope and history rhyme, and he talks about
22	I was due to appear on a live TV debate with	22	cures and healing wells.
23	the Minister.	23	I hope that by looking at the history, that this
24	But one of his rationales for the delay was that	24	Inquiry can meet the hope of the community for
25	they were engaged in negotiations with the 93	25	answers, for acknowledgement, for a sense of 94
1	restitution, and that, in fact, when the report is	1	statistics, but also standards in public life, and
2	published finally, the report will be seen as	2	recommendations which may follow from that, plainly,
3	a healing well by the community, and thank you for	3	that evidence will go to informing. So thank you once
4	the opportunity to give evidence.	4	again, and that's it for today.
5	SIR BRIAN LANGSTAFF: Well, thank you. Thank you very	5	(12.35 pm)
6	much indeed for the most valuable of evidence. As	6	(The hearing was adjourned until 9.00 am on
7	you'll know, we are spending this week and next	7	Wednesday, 9 November 2022)
8	largely on the issues which arise consequent upon any	8	MD DDIANI CIMALIONIV (autom)
9	findings of fact which I might make, none having yet	9	MR BRIAN O'MAHONY (sworn)
10	been finally determined, but you have certainly shone	10	Questioned by MS RICHARDS
11	a very bright light in certain areas which might well	11	
12	feature in recommendations. So thank you for that.	12	
13	MS RICHARDS: Sir, then that's it for today.	13	
14	SIR BRIAN LANGSTAFF: Yes, but tomorrow we have a very	14	
15	early start, don't we?	15	
16	MS RICHARDS: We do, we have a long day tomorrow, sir.	16	
17	We start at 9.00 am with the evidence of	17	
18	Lord Evans, who is chair of the Committee on Standards	18	
19	in Public Life.	19	
20	SIR BRIAN LANGSTAFF: Yes.	20	
21	MS RICHARDS: And I anticipate his evidence will take an	21	
22	hour or say, an hour, maybe an hour and a half. Then	22	
23	we have the postponed evidence from the statisticians.	23	
24	So it will be a full and long day.	24	
25	SIR BRIAN LANGSTAFF: So a full day tomorrow, largely	25	
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