1	Thursday, 19 January 2023	1	sons were all diagnosed with severe haemophilia A in the
2	(10.00 am)	2	late 1970s and early 1980s and their care took place at
3	SIR BRIAN LANGSTAFF: Yes, Ms Gollop.	3	Birmingham Children's Hospital under, then, Dr Frank
4	Closing Statement by MS GOLLOP KC	4	Hill.
5	On behalf of 20 individual Core Participants and	5	Elisabeth discovered that two of her three sons,
6	The Haemophilia Society	6	Richard and Jonathan, were infected with HIV when she
7	MS GOLLOP: Good morning, sir. Good morning, everybody.	7	saw a list of names on the hospital fridge. As she says
8	These are the submissions on behalf of The	8	in her statement:
9	Haemophilia Society. They are also submissions of	9	"Dr Hill was concerned that our knowing of
10	a number of people with Core Participant status,	10	a positive diagnosis would change our relationship with
11	represented by my solicitors, Eversheds Sutherland.	11	our child. There was no treatment and nothing could be
12	They include Elisabeth and Jonathan Buggins, and	12	done about the results. That was the attitude."
13	some of you may remember listening to Elisabeth, who was	13	Her son Richard died in 1986 at the age of eight and
14	on a panel of parents with infected children; Sharon	14	she gave evidence in October last year on the panel that
15	Lewis, [^] name who is the widow of John Prothero,	15	l just mentioned.
16	a member of the Executive Committee in the 1980s; Andrew	16	, Her son Jonathan has made a statement to the
17	Martin, Aname Paul Sartain, and David Watters, whose	17	Inquiry, not yet disclosed. His elder brother was
18	evidence many of you will also remember, he was the	18	Richard, the one who died in 1986, and Jonathan's
19	general secretary of the Society also in the 1980s.	19	statement addresses the impact of his treatment at the
20	I also represent 14 other individuals who would	20	Birmingham Children's Hospital and of being infected.
21	prefer not to be named. I am going to say a brief	21	When he was 12, his parents brought a medical negligence
22	something about those, some who do wish to be named,	22	compensation claim on his behalf which was settled at
23	just so you understand where they're coming from.	23	, trial shortly before Dr Hill was due to give evidence,
24	Elisabeth Buggins, the mother of four children, one	24	when Dr Hill's employer offered £75,000, which sum was
25	of them Jonathan, three sons and a daughter. Her three	25	accepted. And in his statement, Jon gives important
	1		2
1	views on litigation: how he feels it does not improve	1	to my health, and it has been a shock to discover that
2	patient safety and it enables organisations and	2	we were not being protected or at least provided with
3	individuals to hide, escape their responsibility, and	3	the information that the Government or clinicians knew."
4	obstruct the search for the truth.	4	Paul Sartain has made a statement which is available
5	Sharon Lewis, John Prothero's widow, has made	5	on the website. He was diagnosed with severe
6	a statement which has also not yet been disclosed. When	6	haemophilia A in 1970 and affected with hepatitis B
7	it is, I very much recommend reading it. It's	7	and C. And he says:
8	WITN3107001.	8	"In my view, my parents and/or I did not think to
9	John Prothero, her husband, died from the	9	ask about risks because my treatment, cryoprecipitate or
10	consequences of an HIV-related infection on 19 October	10	Factor VIII, was to ease the pain and suffering from
11	1989, when he was 45 years old. He was the Society's	11	a bleed. Many times as a young child I would have
12	treasurer and a board member, and she says in her	12	countless nights of disturbed sleep, pray for the pain
13	statement that, during the course of John's life, he	13	to go away, and/or violently shake my head until I was
14	campaigned for the interests of people with haemophilia	14	so dizzy and feeling nauseous that I'd slump back on to
15	to be advanced in terms of achieving access to justice,	15	my bed in a state of stupor."
16	acknowledgement of their situation, and also recompense	16	And lastly, something about David Watters. He was
17	in relation to the consequences that had befallen the	17	the coordinator and general secretary between 1981 and
18	haemophilia community.	18	1994. He has made a statement, which is available, and
19	Andrew Martin has made a statement which is	19	he gave evidence on 10, 11 and 12 February 2021. David
20	disclosed and not quite yet on the website. He has	20	says his heart aches for victims of infected blood and
21	haemophilia A. He was diagnosed with hepatitis C at	21	he said:
22	some point in or around 1993. And he says:	22	"[He] won't ever forget the good friends on the
23	"When I was diagnosed with hepatitis C, my mother	23	Executive Committee and throughout the Society who
24	was very quick to say that it was her belief that no	24	I lost through HIV and AIDS and who I remember with
25	doctor would ever do anything that would be detrimental	25	affection."
	3		4

1	The Society asks the Inquiry to find that it and its
2	members were fortunate to have the services of
3	Mr Watters. Prior to joining the Society he was
4	a social worker and he worked particularly with homeless
5	people. And after leaving the Society, which he did not
6	want to do, he worked for another healthcare-related
7	charity. His motivation throughout his professional
8	life was to improve the lives of others less fortunate
9	than himself, and he worked tirelessly in pursuit of
10	that goal. He advocated for people with haemophilia at
11	benefit tribunals. He campaigned for financial relief
12	for those infected with HIV. He was there at the start
13	of the campaigns for hepatitis C compensation. And he
14	was a gifted administrator. He and the Reverend Tanner
15	were patently good men doing the best they could for the
16	entire bleeding disorder community in close to
17	impossible circumstances. And you will all know that
18	the Reverend Tanner's son Mark died of infected blood
19	related illnesses and was ill throughout much of the
20	time that the Reverend Tanner was chair of the Society.
21	Those are the pen portraits. I now want to quote
22	from two reports. The first quotation is the same one
23	that Mr Snowden gave you on Tuesday from the
24	Bishop Jones' November 2017 report on Hillsborough.
25	That was the crush at a football stadium in April 1989 5

through this Inquiry in July 2020. Some of the matters
 into which her review inquired dated back to 1950, very
 similar to this Inquiry. The passage of time and the
 fact that attitudes, cultures, communication, and so on,
 have changed over the decades did not prevent the
 Baroness from getting to the heart of the matter and
 they won't stand in your way, sir, either.

Much of the evidence of this Inquiry corroborates her conclusion, and this is what she said:

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10 "We have found that the healthcare system in which I include the NHS, private providers, the regulators, 11 12 and professional bodies, pharmaceutical and device 13 manufacturers and policy makers, is disjointed, siloed, 14 unresponsive and defensive. It doesn't adequately 15 recognise that patients are its raison d'etre. It's 16 failed to listen to their concerns and when belatedly 17 it's decided to act it has too often moved glacially. 18 Indeed, over these two years we have found ourselves in 19 the position of recommending, encouraging and urging the 20 system to take action that should have been taken long 21 ago. The system is not good enough at spotting trends 22 in practice and outcomes that give rise to safety 23 concerns. Listening to patients is pivotal to that." 24 It all sounds horribly familiar. First Do No Harm 25 is a document which I will come back to, if I have time,

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1	which caused almost 100 deaths. Mr Snowden quoted that
2	part of the report where the Bishop explained how he
3	came by the phrase "the patronising disposition of
4	unaccountable power" and talked about the experience of
5	the Hillsborough families when, in all innocence and
6	with a good conscience, they asked questions of those in
7	authority on behalf of those they loved, and found the
8	institutions closing ranks.
9	He went on to say this:
10	"And so the Hillsborough families' struggle to gain
11	justice for the 96 has a vicarious quality to it so that
12	whatever they can achieve in calling to account those in
13	authority is of value to the whole nation."
14	"The concerns that it deals with are both historic
15	and contemporary."
16	That applies just as much to all of you. Everything
17	that you've done has had the same vicarious quality to
18	it, and everything that you have done will be of benefit
19	to the nation. The concerns of this Inquiry go further
20	back even than the events of Hillsborough, and as
21	yesterday's submissions on behalf of the DHSC, to which
22	I'll return in a moment, amply demonstrate, they are not
23	only contemporary, but pressing.
24	The second quotation is from Baroness Cumberlege's
25	report <i>First Do No Harm</i> , and that was published midway 6
	0
1	so I'd like to put it on screen so that those of you who
•	
2	are understandably not familiar with it can see the
3	are understandably not familiar with it can see the similarities here.
3 4	are understandably not familiar with it can see the similarities here. Thank you, Lawrence. You're ahead of me, which is
3 4 5	are understandably not familiar with it can see the similarities here. Thank you, Lawrence. You're ahead of me, which is great. Page we've got paragraphs 1.1 to 1.3 and
3 4 5 6	are understandably not familiar with it can see the similarities here. Thank you, Lawrence. You're ahead of me, which is great. Page we've got paragraphs 1.1 to 1.3 and those are on internal page 0009. That looks like 18.
3 4 5 6 7	are understandably not familiar with it can see the similarities here. Thank you, Lawrence. You're ahead of me, which is great. Page we've got paragraphs 1.1 to 1.3 and those are on internal page 0009. That looks like 18. That's it.
3 4 5 6 7 8	are understandably not familiar with it can see the similarities here. Thank you, Lawrence. You're ahead of me, which is great. Page we've got paragraphs 1.1 to 1.3 and those are on internal page 0009. That looks like 18. That's it. It's really close type. I don't know if we can
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3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	are understandably not familiar with it can see the similarities here. Thank you, Lawrence. You're ahead of me, which is great. Page we've got paragraphs 1.1 to 1.3 and those are on internal page 0009. That looks like 18. That's it. It's really close type. I don't know if we can enlarge 1.2. Very briefly, so that it makes sense, this is what she was looking at: hormone pregnancy tests, which were taken off the market in the late 1970s, thought to be associated with birth defects and miscarriages; sodium valproate, which is an anti-epileptic, which causes physical malformations, autism and development delay in children when taken by their mothers in pregnancy; and pelvic mesh implants used in the surgical repair of organ prolapse and to manage urinary incontinence, linked to crippling, life-changing complications. If we look at page 0011, she identified right at the bottom 16 common and compelling themes which chime very much with your experiences. Number 1:

4		4	
1	"Lack of awareness of who to complain to and how to	1	All of that will be horribly familiar to all of you.
2	report adverse events;	2	Thank you, Lawrence. You can take that down.
3	"the struggle to be heard;	3	To that list, I would add two things. The first and
4	"not being believed; "diamicsive and unbelaful attitudes on the part of	4	lesser is the indignity, harshness and hostile nature of
5	"dismissive and unhelpful attitudes on the part of	5	the so-called support schemes. The other more important
6	some clinicians;	6	matter is death and bereavement. There are no words
7	"a sense of abandonment;	7	that can truly capture the depth and intensity of
8	"life-changing consequences, not only for those	8	suffering that you have recounted to us. Some witnesses
9	directly affected, but for their families and friends	9	may have found making statements or giving oral evidence
10	too;	10	cathartic but, for others, it's been traumatic. They've
11	"breakdown of family life;	11	been through so much, and everybody at the Society is
12	"loss of jobs, financial support and sometimes	12	humbled and deeply grateful to them for suffering
13	housing;	13	further through telling us about it.
14	"loss of identity and self-worth;	14	Doctors really struggle to talk to patients about
15	"a persistent feeling of guilt;	15	risk in a way that gives patients the information that
16	"children becoming their mothers' and siblings'	16	they need and enables everyone to make the choice that
17	carers"	17	is right for them as an individual.
18	We might say fathers', husbands', brothers':	18	Informed choice is the heart of what went wrong over
19	"clinicians untutored in the skills they need to	19	and over again. Safe treatment was taken away by the
20	make a proper diagnosis;	20	Government so that it was not an available choice, or
21	"clinicians not knowing how to learn from parents;	21	doctors consciously or unconsciously took that choice
22	"inaccurate or altered patient records;	22	away because they acted without thinking or thought they
23	"a lack of interest in, and an inability to deliver	23	knew best. There can be no more compelling teaching
24	the monitoring of adverse outcomes and long-term	24	tool than the firsthand accounts of what infected blood
25	follow-up across the healthcare system."	25	has done to you and that you have provided to us 10
	0		
1	selflessly by giving us the evidence that you have done,	1	high standard to further the work of the Inquiry and
2	and allowing it to be captured on camera. Thank you.	2	provide statements and submissions that, so far as can
3	Thank you too to the Inquiry. The kindness, calm,	3	be seen from the outside, are clear, thorough and
4	and consistency of the front-of-house staff, their	4	meticulously searched and referenced.
5	regular meetings around the country, the absolute	5	Ms Grey said as little as she did because her
6	professionalism of the legal team, we know this more	6	client, the Department of Health and Social Care,
7	than you do because we lawyers watch other lawyers, but	7	provided her with nothing more that she could say. The
8	it really has been the best of the best and the	8	fault and the responsibility lies not just with the
9	technical teams.	9	Department she represented but the whole of the Cabinet,
10		3	Department she represented but the whole of the Cabinet,
10		10	
11	Sir Brian, your attention to detail and your very	10 11	from the Prime Minister down.
11 12	personal involvement have been notable features every	11	from the Prime Minister down. When we were informed at the end of the day on
12	personal involvement have been notable features every single day of this long-running Inquiry. If the culture	11 12	from the Prime Minister down. When we were informed at the end of the day on Tuesday that the Department's submissions would not
12 13	personal involvement have been notable features every single day of this long-running Inquiry. If the culture that your vision for your Inquiry has created could be	11 12 13	from the Prime Minister down. When we were informed at the end of the day on Tuesday that the Department's submissions would not start at 10.00 as timetabled but instead at 2.00, and be
12 13 14	personal involvement have been notable features every single day of this long-running Inquiry. If the culture that your vision for your Inquiry has created could be exported into the NHS and Government more widely, that	11 12 13 14	from the Prime Minister down. When we were informed at the end of the day on Tuesday that the Department's submissions would not start at 10.00 as timetabled but instead at 2.00, and be over by 3.00, there were a lot of questions about what
12 13 14 15	personal involvement have been notable features every single day of this long-running Inquiry. If the culture that your vision for your Inquiry has created could be exported into the NHS and Government more widely, that would be grounds for hope for a state that is more	11 12 13 14 15	from the Prime Minister down. When we were informed at the end of the day on Tuesday that the Department's submissions would not start at 10.00 as timetabled but instead at 2.00, and be over by 3.00, there were a lot of questions about what that might mean. There was, within the Society,
12 13 14 15 16	personal involvement have been notable features every single day of this long-running Inquiry. If the culture that your vision for your Inquiry has created could be exported into the NHS and Government more widely, that would be grounds for hope for a state that is more listening, compassionate and responsive to the needs of	11 12 13 14 15 16	from the Prime Minister down. When we were informed at the end of the day on Tuesday that the Department's submissions would not start at 10.00 as timetabled but instead at 2.00, and be over by 3.00, there were a lot of questions about what that might mean. There was, within the Society, a degree of expectation that the submissions were going
12 13 14 15 16 17	personal involvement have been notable features every single day of this long-running Inquiry. If the culture that your vision for your Inquiry has created could be exported into the NHS and Government more widely, that would be grounds for hope for a state that is more listening, compassionate and responsive to the needs of those it here to serve.	11 12 13 14 15 16 17	from the Prime Minister down. When we were informed at the end of the day on Tuesday that the Department's submissions would not start at 10.00 as timetabled but instead at 2.00, and be over by 3.00, there were a lot of questions about what that might mean. There was, within the Society, a degree of expectation that the submissions were going to be short because the Government had something of
12 13 14 15 16 17 18	personal involvement have been notable features every single day of this long-running Inquiry. If the culture that your vision for your Inquiry has created could be exported into the NHS and Government more widely, that would be grounds for hope for a state that is more listening, compassionate and responsive to the needs of those it here to serve. Which brings me to yesterday. We're all familiar	11 12 13 14 15 16 17 18	from the Prime Minister down. When we were informed at the end of the day on Tuesday that the Department's submissions would not start at 10.00 as timetabled but instead at 2.00, and be over by 3.00, there were a lot of questions about what that might mean. There was, within the Society, a degree of expectation that the submissions were going to be short because the Government had something of substance to announce. Instead, time that could have
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1	have happened, the Department had somehow gone backwards	1
2	and is now unable to identify what it was sorry for when	2
3	the Inquiry started. There's been some sort of	3
4	groupthink amnesia.	4
5	Ms Grey referred to the fact that on 15 December,	5
6	the Cabinet Secretary told the House of Commons that the	6
7	Government accepted moral responsibility for infected	7
8	blood but, yesterday, it was unable to say through its	8
9	lawyers why it has accepted moral responsibility or what	9
10	that actually means.	10
11	My clients accept that they cannot force the	11
12	Department to say what it is sorry for. Sir Brian had	12
13	a go, and if he can't make that happen then neither can	13
14	we. But the cowardly approach taken by the Department	14
15	has three consequences: first, what little trust there	15
16	might have been has gone.	16
17	Second, and this was not the Society's position	17
18	before yesterday afternoon, it now joins with the	18
19	submissions of Mr Snowden, King's Counsel, on behalf of	19
20	those represented by Collins, that there need to be	20
21	further interim recommendations on compensation for	21
22	parents, children and grandchildren who have been	22
23	bereaved by infected blood. The payments of £100,000	23
24	were only paid because, Sir Brian, you made an interim	24
25	recommendation in that regard. Bereaved people have had 13	25
1	to read. Baroness Neville-Rolfe, who is the Minister	1
2	for the Government in the House of Lords, said that	2
3	Ms Sue Gray, at the Cabinet Office, is bringing together	3
4	permanent secretaries from the Treasury, HMRC, the	4
5	Cabinet Office, DHSC, the DWP, the DLUHC, (I think	5
6	that's the levelling up and) the Develved Nations and	6

6 that's the levelling up one), the Devolved Nations and 7 others. She told the House of Lords that this group met 8 monthly and that -- this is a quote:

9 "It is gearing up, thinking about the IT systems and 10 how we ensure that we contact people who might want to 11 seek compensation, once we know the precise framework 12 and make sure that everyone can respond. Publicity is 13 very important with these public issues and noble Lords 14 across the house can help with that so that people know 15 what is happening."

16 She then said that careful consideration was being given as to whether there should be an arm's length 17 18 body. She said the Government would want to work with 19 "people affected" and acknowledged the work of the APPG. 20 She said she'd make progress statements to the 21 house. On 11 January this year, in a written answer to 22 a Parliamentary question, Mr Quin said that the 23 cross-Government working party was taking forward work 24 on the establishment of an arm's length body. 25 The Society makes three points. The first is about 15

1	nothing and they deserve something now. There is no
2	reason to believe that the Government will do anything
3	without a recommendation from you.
4	Third, it is absolutely imperative now that this
5	Inquiry does not end with the publication of the report.
6	For as long as your Inquiry is alive, Sir Brian, people
7	have trust and hope that there will be accountability,
8	compensation and lasting change. The fear is that, as
9	soon as you close this Inquiry, there may be delay,
10	backsliding and nothing will really change. We would
11	not want see your report to be as widely disregarded as
12	it would appear Bishop Jones' report into Hillsborough
13	has been.
14	Yesterday rather proved that that fear may well be
15	well founded. A way must be found to hold the
16	Government's feet to the fire after the report is
17	published.
18	Ms Grey mentioned Mr Quin's statement in the House
19	of Commons on 15 December. We would mention the debate
20	in the House of Lords on 20 December last year, five
21	days later. I've given the reference to Ms Richards,
22	and we'll make that reference available to you,
23	Sir Brian.
24	There is a transcript of the debate on the
25	TheyWorkForYou.com website, which you may be interested 14

the need for the working group to listen to infected and affected people's views on the compensation framework they want and need now, not when the finished product is delivered. Returning briefly to the Government's implementation 6 of the Cumberlege Review's recommendations, the Society 7 notes -- and it's one of my New Year's resolutions to 8 stop bombarding Ms Richards with emails telling her to listen to Woman's Hour -- that she gave an interview to 9 10 the BBC -- there was an interview on Woman's Hour on 3 January 2023, given by the Patient Safety 11 12 Commissioner. That was a recommendation of Baroness 13 Cumberledge's report and Dr Henrietta Hughes has been in 14 post for some months now. 15 Dr Hughes talked about the mesh removal centres 16 which have been set up in response to the Cumberlege 17 Review's findings and Dr Hughes told the BBC that these 18 centres are not meeting the needs of users because when 19 the clinics and systems were designed, the views of the 20 women harmed by mesh were not listened to. The Society 21 is concerned that the same error may be being repeated 22 right now in relation to the working group setting up 23 the infected blood compensation framework. 24 Second, transparency. The Society would suggest --25 and, Sir Brian, we might like to tempt you into 16

1

There's still time.

1	considering an interim recommendation that it is
2	reasonable to ask that we have published (i) the names
3	and members of the working group; (ii) the dates of
4	their meetings and the agenda and minutes; and (iii)
5	that there are regular publicly available written
6	progress reports. Infected and affected people
7	shouldn't have to scour the Internet looking for reports
8	of debates in the House of Lords to find out what is
9	going on. If the working group wanted to report, they
10	could do so to this Inquiry and keep this Inquiry in the
11	loop, not just make statements in the House of Lords.
12	Third, just going back to that quote about what the
13	working group is currently doing, thinking about the IT
14	systems and how we ensure that we contact people, it's
15	hard to know where to start.
16	Shout out to Baroness Neville-Rolfe and her
17	colleagues: come on down to Aldwych House. People here
18	are very nice. They don't bite and you can talk to them
19	and you can listen to them and you can find out what
20	they need, and there are a whole load of people sitting
21	behind me who could probably give you the list of people
22	to contact right here and right now. You really don't
23	need to ask members of the House of Lords to do your
24	publicity work for you. It's all here, handed on
25	a plate, if you would only like to come and listen.
	17
1	Before I look at those a word about money and the

1 Before I look at those, a word about money and the 2 cost of haemophilia. I'm going to quote from a document 3 that's on the website which is a collection of pieces from the British Medical Journal, and I give a trigger 4 5 warning that it contains language and an ethical stance 6 which may be offensive. It goes without saying that the 7 Society wants to make it very clear that it's not its 8 position that anyone in Government or the NHS intended 9 the death of any patient or section of the public but 10 that this is an important part of the context of the lives of people with haemophilia at the beginning of the 11 12 1970s. 13 The Society was always mindful that if NHS money was 14 going to be spent on haemophilia treatment, the 15 Government would want to see that justified financially, 16 but there was actually more at stake. In 1971, the BMJ 17 published a profile opinion piece that had coverage in 18 the national press, arguing that the successful 19 treatment of haemophilia, especially for severe cases, 20 was enabling not only the survival of these high-demand 21 patients but also their likelihood of having children. 22 This is the quote: 23 "If we continue the policy of treating such 24 sufferers with the full resources of modern medicine, we 25 shall spend a steadily increasing proportion of the 19

2 You've had a long time to think about what you want 3 and what you need from a compensation framework. You 4 should be in the tent, not outside it. 5 I'm going to turn now to the past. These 6 submissions look at the past, the present and the 7 future. They're focused on the future because that's 8 where the Society can make a positive difference for 9 people who are suffering now and for future generations 10 of people with a bleeding disorder. In not touching on 11 the past at greater length, the Society isn't seeking to 12 evade scrutiny, and we have tried to explain its 13 knowledge of risk and its actions, particularly in the 14 1980s, as thoroughly as possible in written submissions. 15 We've asked the questions: why did the Society 16 support the importation into the UK of US blood product 17 that it knew carried a higher hepatitis risk than UK 18 treatment, before the UK had achieved self-sufficiency? 19 From '83 to '85, why did it tell its members that 20 the risk of being treated with US products and getting 21 AIDS was outweighed by the risk of not being treated at 22 all and why did it press the Government to continue 23 importing US products that it knew could be contaminated 24 with AIDS even when it was known that AIDS was a killer 25 disease for which there was no cure? 18

1	national income for their benefit and reduce the
2	proportion available for the care of other forms of
3	illness, education, technical development, and so on.
4	Are we prepared to pay such a price and increase the
5	number of biochemical cripples fourfold in a generation?
6	Is not this too high a price to pay for our comfortable
7	glow of companionable humanity?"
8	Later correspondence in the BMJ was consistently
9	critical of that stance and there was never any further
10	discussion of eugenics with regard to haemophilia.
11	But the cost of keeping people with haemophilia
12	alive has never gone away. One thinks, for example, of
13	the Society's campaign for Recombinant for All in the
14	late 1990s and the fight to get that extended from
15	children to adults and the restricted access on cost
16	ground to Harvoni, for example, that was still taking
17	place as late as 2016, the year before this Inquiry was
18	announced.
19	When preparing for the Archer Inquiry, one of the
20	documents that the Department of Health was concerned
21	might cause some embarrassment was a March 1985
22	document, and that was a memo that said:
23	"Steps to prevent the remainder of the haemophiliac
24	population becoming seropositive are likely to have
25	a strong cost benefit plus in terms of lives saved. Of 20

25

1	course, the maintenance of the life of a haemophiliac is
2	itself expensive and I'm very much afraid that those who
3	are already doomed will generate savings which more than
4	cover the cost of testing blood donations."
5	A few points may be made. First, and most
6	obviously, the fact that lives of people with
7	haemophilia is expensive is not the fault of
8	haemophiliacs. People with rare diseases exist in every
9	population and in countries with a developed healthcare
10	system, part of the duty of government is to protect
11	them as much as everybody else. Second, freeze dried
12	large pool concentrates were welcomed partly because
13	they were seen as an improved means of enabling the
14	bleeding disorder community to make a financial
15	contribution.
16	In 1979, the Department of Health and Social
17	Services sponsored a study into home treatment and found
18	that it "provided savings in time lost from school and
19	work, a greater sense of security, and increased
20	capacity for planning ahead".
21	In 1989 the Reverend Tanner wrote to Norman Lamont
22	seeking more financial support for people with
23	haemophilia infected with AIDS and explained that "they
24	became infected through their use of prescribed
25	medication in an earnest desire to maintain their health 21
1	commissioning a study to look at the financial

1	commissioning a study to look at the financial
2	contribution people with haemophilia could make by using
3	home treatment, working, and contributing to the
4	economy. And six years later, in 1985, the Department
5	was taking into account the contribution they would make
6	to the cost of testing for AIDS by dying of AIDS.
7	People with haemophilia were vulnerable physically
8	and psychologically. They grew up knowing that they
9	were expensive to treat. Some of them had had shortages
10	of treatment or rationing. They were deeply grateful
11	for cryo and the knowledge that their children were not
12	going to die in their twenties but live a long life.
13	And they were grateful again for concentrate and home
14	treatment. They were dependent on other people's
15	willingness to give blood, on taxpayers, on continued
16	Government funding of the treatment that kept them alive
17	and healthy. And from 1973, many of them were made
18	dependent on US commercial pharmaceutical companies.
19	Above all, they were dependent on their doctors,
20	whom they trusted to act in their best interests in the
21	same way that the Society trusted Professor Arthur Bloom
22	and other members of its advisory panel.
23	These were not relationships between equals and all
24	of these factors are the context for the decisions made
25	by the Society.

23

1	and play an active role in society".
2	Third, the maintenance of the lives of people with
3	haemophilia would have been less expensive if
4	self-sufficiency had been achieved by 1977, as Dr Owen
5	and the Medical Research Council said it would have
6	been. As doctors frequently pointed out to Government,
7	if it stopped paying a lot of money for expensive
8	commercial blood products to US pharma, it would recoup
9	the capital cost of rebuilding BPL in a relatively short
10	period of time.
11	Fourth, had there been better co-operation between
12	the British and Scottish blood services, and any
13	Governmental drive to use the fractionation capacity of
14	Liberton, again, the lives of people with haemophilia
15	would have been less expensive.
16	And fifth, a person born with haemophilia doesn't
17	come with a set price tag attached. It was within
18	Government's power to control the amount of taxpayers'
19	money spent on them. As other Core Participants have
20	pointed out, Government could have limited the amount of
21	money regions were allowed to spend on Factor VIII, or
22	made a decision not to fund prophylaxis or to limit home
23	treatment, and it was Government's choice to move away

from cryo and move on to large pool concentrates.

So in 1979 we had the Department of Health 22

1	The next point is Government responsibility.
2	It's Government's responsibility to consult with
3	a section of the population such as those with
4	a bleeding disorder and any charity that advocates for
5	their rights, but decisions about how to allocate
6	resources are for Government, not for patients and not
7	for little charities that represent patients. What
8	medicines should be licensed for use in the NHS, whether
9	they should be manufactured by the NHS or private
10	companies, whether those companies should be based in
11	the UK or abroad, how much treatment is made available
12	to which patients, and where, these are decisions for
13	Government and for the NHS, not for patients. That was
14	particularly the case in relation to the funding of
15	haemophilia care in the '60s, '70s and '80s, where there
16	was a distinct power imbalance and a patient dependency
17	and vulnerability.
18	The duty of advising patients about whether they
19	needed a treatment with blood or a blood product, what
20	the choices were, what the treatment recommendation was
21	and why, the risks and benefits, that was the duty of
22	doctors. It was not the duty of the Society.
23	So why did does the Society support the switch from
24	cryo to concentrate and support importation of US
25	products? Very simply, cryo gave you a long life. 24

1	Concentrate allowed you to live your life to the full.	1	provision. There's a report in a 1974 Bulletin of the
2	What home treatment took away, and it's probably not	2	Society offering a hospital assistance with volunteer
3	possible for those of us who don't have a bleeding	3	workers to help increase production of cryo, and the
4	disorder to understand this, was the pain of an	4	response from the hospital was that that help might be
5	untreated bleed, the fear of pain, and the spectre of	5	resented by technical staff and could result in
6	bleed-induced permanent disability.	6	industrial action.
7	In January 1972, the Society republished an	7	If you read The Bulletins of the time, there are
8		8	-
9	editorial from The Practitioner, a journal which is primarily aimed at GPs which tells you something	9	a host of examples, and we've given them in our written submissions, of what the Society was doing to try to
9 10	about how widespread was the state of knowledge at that	9 10	make treatment available to people across the country,
10	time and the editorial talked the reader through the	10	providing home freezers and all sorts of things like
12	work of J Garrott Allen in 1970 which identified the	12	that.
		12	
13	fact that commercial blood is riskier than voluntary		In 1974, Dr Biggs published a letter in The Lancet
14	blood. And the piece in The Bulletin explained why:	14	saying that there was a shortage of treatment and that
15	paid blood came from prisoners, people on skid row,	15	90 per cent of UK patients were getting less than the
16	people addicted to drugs and alcohol.	16	optimum treatment for their complaint. Non-urgent
17	So the Society knew that in 1972, before the first	17	operations were being cancelled and there was a delay in
18	US products were licensed in 1973, and it made that	18	putting patients on home treatment.
19	knowledge available to anyone who read The Bulletin.	19	In that context, the Society supported an increase
20	At the time, the NHS wasn't producing enough	20	in the supply of concentrate, but there's no evidence
21	cryoprecipitate or concentrate to meet the needs of	21	that it campaigned for licences to be issued so that
22	patients, and that was a concern to the Society. The	22	blood products could be imported from America. The
23	Society didn't particularly mind what form the treatment	23	minutes of the meetings of the Centre Directors in
24	took so long as there was enough of it to go round, and	24	October '72 and January '74 record that it was the
25	it did whatever it could to plug gaps in the NHS 25	25	Centre Directors who were pressing for permission to do 26
	20		20
1	that and that, given the choice, none of the Centre	1	Chris James, the Society's chief executive at the time,
2	Directors preferred to use cryoprecipitate; they all	2	summarised the efforts that the UKHCDO went to in 1977,
3	preferred to use concentrate Factor VIII.	3	'78, and 1980. That's ARCH0001014.
4	It was David Owen who was the Health Minister when	4	So in all of those years, the UKHCDO was trying to
5	American blood products were licensed for use in the NHS	5	impress on Government that it needed to hurry up with
6	in '73. As he explains in his witness statement, he	6	self-sufficiency with the same lack of success. So in
7	knew what he was doing. He had reviewed Titmuss' book	7	the early '70s there might have been some knowledge
8	for the New Statesman in 1971 and he identified in his	8	amongst some members of the bleeding disorder community
9	review the fact that there was no moral, financial or	9	that large pool concentrates had an increased hepatitis
10	administrative case for using US products in the NHS.	10	risk and that US products were worse than NHS ones, but
10	He knew the risks to the bleeding disorder community	10	what you know and what you really get and understand are
12	that he was sanctioning. This was a stopgap measure.	12	two different things.
12	And when he made it possible for US blood products to	12	And the World in Action documentaries were eye
13	come into the country in '73, he committed the	13	opening. So this is a good point to replay part of the
14 15	Government to self-sufficiency by 1977.	14	second documentary broadcast in December 1975, where
15 16	That was the aim. The problem was that the aim	15	patients, parents and the Society's Executive Committee
10	wasn't achieved, and there was never a plan B. The	10	were asked for their reactions to the first broadcast,
17	Society was concerned at the time that that date was	17	which showed how blood was collected in the US on skid
19	going to be missed. It spoke to Dr Owen at the end of	18	row and the added risks of products.
	1975, talked to him about what could be done, about	19 20	
20 21			Take it away, please, Lawrence.
21 22	plasmapheresis, the regional structure of BTS and other	21 22 N	(Video played)
22 23	matters, and repeatedly expressed its concern about increasing reliance on US commercial concentrates, but	22 1	MS GOLLOP: Sir, I see the time and I'm told that cometh the time, cometh the Paddington hard stares from the bench.
	nothing changed.	23 24	So I don't know if this is marmalade sandwich time or
24 25	In his letter to the Archer Inquiry in August 2007,	24	not?

1	SIR BRIAN LANGSTAFF: Well, I think it might be a bit early,	1
2	if there are, let's say, a few more minutes that you can	2
3	take us up to, say 11.15.	3
4	MS GOLLOP: Yes, with pleasure.	4
5	Well, that was December 1975. Probably, one	5
6	imagines, filmed not long before the Society had its	6
7	meeting with David Owen and talked to him about	7
8	plasmapheresis and other things that could speed up	8
9	production in this country.	9
10	I want to fast forward, if you'll come with me, to	10
11	1983, and the Society's May advice. Despite its	11
12	contacts with civil servants and the doctors on its	12
13	Medical Advisory Panel, when it came to the two	13
14	infections that destroyed so many lives, including the	14
15	lives of those who you've just seen talking, the Society	15
16	had just as few facts and as little reliable information	16
17	about risk as any patient with haemophilia.	17
18	The Inquiry has produced an impeccable chronology of	18
19	the knowledge of risk. When it comes to what the	19
20	Society knew, it's as important to look at what it	20
21	didn't know but could have been told, as to what it did	21
22	know. The Society trusted people with knowledge in the	22
23	NHS and in the Civil Service to share what they knew in	23
24	the way that the Society shared what it knew with those	24
25	people. But this was not an information two-way street.	25
	29	
1	cases in the United Kingdom."	1
2	It is truly shocking to read that letter alongside	2
3	Professor Bloom's advice to the Society and its members	3
4	two months later. It's clear from all of his actions	4
5	that Dr Evatt wanted the facts about AIDS and the threat	5
6	of AIDS to people with haemophilia to be widely known.	6
7	He was doing everything he could to get the word out.	7
8	This was not, in any sense, a confidential letter.	8
9	Professor Bloom could and should have shared it with the	9
10	Society.	10
11	As Mr Snowden pointed out on Tuesday, ten days after	11
12	the date of that letter, on 17 March 1983, Professor	12
13	Bloom diagnosed AIDS in his own patient with	13
14	haemophilia, Kevin Slater, and it was less than two	14
15	months later that he gave advice to the Society and its	15
16	members that:	16
17	"The cause of AIDS is quite unknown and it has not	17
18	been proven to result from transmission of a specific	18
19 20	infected agent in blood products. The number of cases	19
20	reported in American haemophiliacs is small, and in	20
21	spite of inaccurate statements in the press, we are	21
22	unaware of any proven case in our own haemophilic	22
23	population."	23
24 25	The Society will never know why Professor Bloom did	24
25	not share with it the letter he received from Dr Evatt	25

	In January 1983, Professor Bloom attended
	a Hepatitis Working Party meeting where Dr Craske talked
	about the information he had had from the CDC in
	America. At that time, there were ten cases of AIDS in
	haemophilia A patients in the States, and it seemed to
	the CDC possible that Factor VIII or other blood
	products might be implicated. That was in January.
	On 7 March 1983 Dr Evatt at the CDC in the States
	wrote to Professor Bloom and he said this "As you can
)	imagine" I think you have to try to imagine
1	an American accent, which I won't do, but, you know,
2	take yourself back to Atlanta:
3	" AIDS is having a major impact on the treatment
1	of haemophiliacs here presently. The evolution of the
5	epidemic is occurring with a frightening pace. We
3	presently have 13 confirmed haemophiliac patients with
7	AIDS in the United States. One of the patients has
3	a Factor IX deficiency, one is bisexual. In addition,
9	five more highly suspect cases are under investigation.
)	The incidence rate has been increasing in haemophiliacs
1	and the epidemic curve parlays that of the total
2	epidemic curve. The first case appeared in
3	a haemophiliac in January 1982, a total of nine were
1	reported by December. Of those, eight died in 1982.
5	I suspect it's a matter of time before you begin to see 30
	in March, with its devastating and accurate warning that
	the epidemic of AIDS amongst people with haemophilia in

	in March, with its devasitating and accurate warning that			
2	the epidemic of AIDS amongst people with haemophilia in			
3	the US was likely to cross the Atlantic and arrive in			
4	the UK. It will never know why he chose consistently to			
5	minimise the risk of AIDS. Before this Inquiry, the			
6	Society did not know the extent of his breach of the			
7	Trust it put in him, and the distress has been			
8	considerable. The Society trusted the doctors providing			
9	it with advice to inform them of the facts and not			
10	withhold them even if the facts were difficult to hear.			
11	It particularly trusted Professor Bloom, who was not			
12	only the UKHCDO chair, but a trusted adviser to			
13	Government at a high level.			
14	He abused the Society's trust.			
15	Other doctors have told the Inquiry that there was			
16	a lot of confusion. There were lots of conflicting			
17	theories. Things that now seemed clear were not clear			
18	then. But facts are facts and Dr Craske and Professor			
19	Bloom had the facts about what was happening in the			
20	States and the CDC's working approach to a likely			
21	epidemic. As you said, Sir Brian, during the			
22	presentation on knowledge of risk, the numbers were			
23	going up. The Society and people with haemophilia were			
24	entitled to know what the numbers were.			
25	As a follow-up to its "Killer Blood" article in the 32			

1	first weekend in May 1983, The Mail on Sunday published	1	"The pattern of the epidemic has suggested that AIDS
2	a further article called "Action to Ban Danger Blood",	2	may be due to an infectious agent transmitted by
3	and that reported a Dr Pinching as saying that, and	3	intimate contact"
4	l quote:	4	So you've got a reference to sex there.
5	"I wouldn't dream of giving a patient American blood	5	" or blood product inoculation, in a way
6	products. We have to find an alternative immediately."	6	reminiscent of hepatitis B virus. While there are many
7	It seems likely, and we invite you to find, sir,	7	other suggested causes, this one currently seems the
8	that it was because of that quote in the national press	8	most likely. The agent is probably a virus but it has
9	that the Society either invited Dr Pinching to write for	9	not been identified, so no tests. A particular problem
10	The Bulletin or he said to the Society he would like to	10	is that there appears to be quite a long period (months
11	write something for them.	11	or years) between the exposure to the causative agent
12	Dr Pinching did not treat people with haemophilia	12	and the person becoming ill, during which time he or she
13	and he wasn't a Centre Director. He was outside the	13	may be infectious."
14	mainstream and, if there was an alternative to the Bloom	14	Then in the second paragraph, starting "Over 2,000
15	view, it was clear from what he had been reported as	15	cases", about four lines down:
16	having told The Mail on Sunday that he would be a good	16	" the disease carries a high mortality."
17	person to provide that counterblast. He did write for	17	Then if you jump a bit further, five or so lines
18	the bulletin and the article he wrote was rather more	18	down:
19	cautious in tone and more informative than what	19	"The syndrome is rightly being viewed with some
20	Professor Bloom had had to say.	20	concern. In the present state of knowledge, a major
21	Lawrence it's PRSE0000411 at page 11. It's squidgy	21	objective must be to try to reduce the risk of
22	writing but hopefully we can make it a bit larger.	22	transmitting the disease further.
23	This is his piece in The Bulletin and, if you look	23	"How does this affect haemophiliacs?"
24 25	on the right-hand column, he tells you really quite	24	He said:
25	a lot: 33	25	"AIDS has affected 1 in 1,000 in the USA and two 34
1	patients in the UK."	1	who shouldn't get it: children, those with mild disease.
2	So you're getting that information.	2	And he says the source of Factor VIII concentrates will
2	"The immediate source of infection in such patients	3	need to be kept under constant review, as will blood
4	is thought to have been Factor VIII concentrate,	4	donor policy, both by the medical profession and the
5	derived, as it is, from thousands of donors."	5	relevant industrial concerns, to minimise or eliminate
6	So you're getting the information about where it's	6	the risk.
7	coming from and the fact that this is large pool	7	Now, two points to make. One, all of that was good,
8	concentrate, very different to cryo.	8	sound advice, with some facts, and the Society would
9	"On the other hand, this new and to some extent	9	have done well to keep repeating it.
10	theoretical hazard of using concentrates has to be set	10	Second, whatever it was that he did or did not say
11	against the enormous benefits, especially for home	11	to the Mail on Sunday, by the time he was writing for
12	therapy. As in any other medical setting the risk has	12	The Bulletin in the middle of 1983, Dr Pinching was
13	to be balanced against the dangers of the disease	13	giving the same advice as Professor Bloom.
14	itself. Factor VIII concentrate from the USA may be the	14	SIR BRIAN LANGSTAFF: Well, was he, or was he simply saying
15	most likely to contain the AIDS agent. However, the	15	the present balance of opinion balance of opinion
16	risk is probably small and no source can be regarded as	16	among Haemophilia Centre Directors he's not actually
17	completely free from risk. Furthermore, the USA is the	17	saying it's his opinion, is he?
18	only country capable of providing the quantity of	18	MS GOLLOP: No, he's not, and one may think that he chooses
19	Factor VIII currently needed by UK haemophiliacs."	19	his words rather carefully. The difficulty with the
20	Then a few lines down:	20	balance of opinion is that it wasn't a balance of
21	"The present balance of opinion among Haemophilia	21	opinion. It was the unanimous opinion.
22	Centre Directors in the UK therefore is that imported	22	SIR BRIAN LANGSTAFF: Well, at the executive level,
23	Factor VIII concentrate should continue to be used for	23	certainly.
24	those selected patients already receiving it."	20	MS GOLLOP: But he says what he says.
25	He sets out who those are. Then he sets out those	25	SIR BRIAN LANGSTAFF: Yes.
	35	20	36

1	
	MS GOLLOP: And he doesn't say
2	SIR BRIAN LANGSTAFF: But he doesn't say what his view is,
3	and that has to be balanced, when I come to look at this
4	and think about it, with what is reported in The Mail on
5	Sunday, and for that matter I recall, whether it was
6	that or whether it was the Northern Echo or another
7	paper, he was recorded saying it was madness to take
8	a blood product from a country in the middle of an
9	epidemic.
10	MS GOLLOP: Yes.
11	SIR BRIAN LANGSTAFF: Which would suggest his view, at least
12	at that time, and for the purposes of that report, if
13	properly reported, was that it shouldn't be admitted
14	into the country. There we are.
15	MS GOLLOP: That's right.
16	And as I said, he is not a haematologist. I think
17	he's an immunologist, so far as we know not patient
18	facing. So he wasn't challenged with what to say to
19	a patient and what to prescribe and that the shortages
20	that there were. But the piece that he wrote is more
21	nuanced and much more helpful than anything than
22	emanated from Professor Bloom.
23	Looking abroad, the risk minimisation measures
24	unanimously adopted by the World Federation of
25	Hemophilia in July 1983 were very similar to the
	37
1	I'm going to play some clips in a moment and, to set
2	the scene, by the time this programme went out we're
3	a decade on from the one we've just looked at, and the
4	programme started by saying that five people with
4 5	programme started by saying that five people with haemophilia had died of AIDS in the UK. It discussed
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5 6 7 8 9	programme started by saying that five people with haemophilia had died of AIDS in the UK. It discussed the numbers of people estimated to be infected in the UK, and we see Dr Peter Jones saying that, for those infected, there's a 90-95 per cent chance that they're going to be all right, and Dr Savidge saying that the
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1	UKHCDO's guidelines. Not a single doctor in the UK
•	
2	contacted the Society to voice any disagreement with the
3	information it published about AIDS between 1983 and
4	1985, and many haematologists have given evidence to the
5	Inquiry about the fact that they made The Bulletin
6	available to patients. The Society's belief from '83 to
7	'85 was that without US concentrates there was not
8	enough blood product in the UK to treat patients, and
9	that if left untreated, patients with severe conditions
10	would suffer bleeds which would certainly cause damage
11	to joints. That was the context in which, in
12	September 1983, the Society urged the Government to
13	continue to import from the US, which was something that
14	the Civil Service had already decided to do in May '83
15	in any event.
16	In essence, the treatment advice from Centre
17	Directors, supported by the Department of Health and all
18	parts of the NHS system, did not change until
19	heat-treated product was universally adopted in 1985.
20	Perhaps the best evidence of how the Society was
21	thinking in this crucial period comes from
22	John Prothero, who you heard at the end of that clip and
23	who, I remind you, died in October 1989, and other
24	people with haemophilia in the July 1985 documentary Bad
25	Blood.
	38

1	situation, and he worked hard to achieve acceptance by		
2	the Government of its moral responsibility towards		
3	people infected by contaminated blood, and he fought for		
4	justice and financial redress for them in the few years		
5	left to him between speaking to you then and his death.		
6	Sir		
7	SIR BRIAN LANGSTAFF: That's plainly a convenient moment.		
8	So we'll take a break, and we'll come back at 11.45. So		
9	11.45.		
10	(11.16 am)		
11	(A short break)		
12	(11.45 am)		
13	SIR BRIAN LANGSTAFF: Yes?		
14	MS GOLLOP: I'm going to make two points in relation to		
15	hepatitis NANB, as it then was. We've addressed this at		
16	• •		
17	going to say more than that about this issue now.		
18			
19			
20			
21			
22			
23	that she escalated a communication of that knowledge up		
_0 24	the chain and sent her memo around the Department quite		
24			
20	widely and to her superiors. So I won't take you back		

1	to that.	1	draws a parallel with non-steroidal anti-inflammatory
2	What I would ask us to do, just very briefly, is	2	drugs, and some patients being relieved of pain by using
3	then fast forward about seven years to Dr Smithies' memo	3	those over-the-counter drugs. And she says:
4	of 17 February 1987. That's DHSC0001383. This is	4	"I find it difficult to advocate that there are any
5	a three-page document and this is the last page.	5	special circumstances surrounding the care of
6	It's worth looking at in a little bit of detail.	6	haemophilia which makes their case for compensation
7	I think we've looked at the first paragraph more than	7	greater than that of other patients who take medicines
8	once, but the second paragraph is of interest as well.	8	which kill them. That is, of course, provided the
9	She talks about the "finite number of haemophiliacs who	9	doctors caring for the patients have prescribed their
10	have contracted HIV infection" and remember this is	10	treatment in a proper manner."
11	February 1987, so significant numbers of people are	11	A few points arise. Number one, the last sentence
12	already, in the haemophilia community, dying of AIDS at	12	is a bit of a big "if" when it comes to infected blood.
13	this point in the UK and their position being	13	The second is, it's a false equivalence between
14	"pitiful", and having "attracted great sympathy", in	14	anti-inflammatory drugs, which one can choose a variety
15	part because of the "perceived stigma".	15	of painkillers and buy over-the-counter, and infected
16	It wasn't just perceived; it was objectively as well	16	blood. It smacks of whataboutery. There are so many
17	as subjectively present.	17	differences, it shouldn't be necessary to spell them
18	Then she says:	18	out.
19	"The equally sad fact that a number of haemophiliacs	19	AIDS at this time had a very high mortality rate.
20	will undoubtedly die of chronic hepatitis as a result of	20	Drugs that you can buy over the counter and take for
21	non-A non-B infection has not been recognised publicly."	21	arthritis if you choose do so really didn't. And it's
22	Which suggests that it's been well known within the	22	a paragraph that seems lacking in compassion and lacking
23	Department privately but somehow not recognised	23	in a sense of the reality of people's lives in
24	publicly. So that's of concern.	24	February 1987.
25	Then a passing interest, she says she makes		SIR BRIAN LANGSTAFF: An example of a non-steroidal
	41		•
	71		42
			42
1	anti-inflammatory drug is something like ibuprofen. And	1	42 which could also be fatal, and from which a number of
1 2		1 2	
	anti-inflammatory drug is something like ibuprofen. And		which could also be fatal, and from which a number of
2	anti-inflammatory drug is something like ibuprofen. And to suggest you're saying, I think, are you that	2	which could also be fatal, and from which a number of them, in Dr Smithies' words earlier that year, were
2 3	anti-inflammatory drug is something like ibuprofen. And to suggest you're saying, I think, are you that somebody who takes ibuprofen suffers stigma for	2 3	which could also be fatal, and from which a number of them, in Dr Smithies' words earlier that year, were undoubtedly going to die.
2 3 4	anti-inflammatory drug is something like ibuprofen. And to suggest you're saying, I think, are you that somebody who takes ibuprofen suffers stigma for instance, or anything equivalent, is not appropriate?	2 3 4	which could also be fatal, and from which a number of them, in Dr Smithies' words earlier that year, were undoubtedly going to die. Given Mr John Moore's reaction to what he heard in
2 3 4 5	anti-inflammatory drug is something like ibuprofen. And to suggest you're saying, I think, are you that somebody who takes ibuprofen suffers stigma for instance, or anything equivalent, is not appropriate? MS GOLLOP: Not very.	2 3 4 5	which could also be fatal, and from which a number of them, in Dr Smithies' words earlier that year, were undoubtedly going to die. Given Mr John Moore's reaction to what he heard in the meeting, it is reasonable to think that he would
2 3 4 5 6	 anti-inflammatory drug is something like ibuprofen. And to suggest you're saying, I think, are you that somebody who takes ibuprofen suffers stigma for instance, or anything equivalent, is not appropriate? MS GOLLOP: Not very. SIR BRIAN LANGSTAFF: No. Thank you. 	2 3 4 5 6	which could also be fatal, and from which a number of them, in Dr Smithies' words earlier that year, were undoubtedly going to die. Given Mr John Moore's reaction to what he heard in the meeting, it is reasonable to think that he would have acted on information about that second killer virus
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1	scientists believe could affect more than ten times as	1
2	many". And Lord Horam's response to that was, "We are	2
3	not talking about those sort of numbers". And by that	3
4	he meant the number of people who were going to be	4
5	infected with hepatitis C, not the amount of money.	5
6	One might think that if the facts that Dr Smithies	6
7	was aware of and that were known within the Department	7
8	in 1987 had been recognised publicly at that time, there	8
9	ought to have been a less dismissive response by the	9
10	Minister in 1996, and there would not have been a decade	10
11	of lost opportunity for properly funded research,	11
12	learning, and improved patient care.	12
13	In our written submissions, we've set out a lot of	13
14	the activity that the Society was engaged on in and	14
15	around hepatitis C in the 1990s and the campaign that	15
16	was started, and where that led to eventually after	16
17	a lot of hard pushing.	17
18	Sir, I'm going to deal briefly with some	18
19	miscellaneous matters, and they are litigation,	19
20	hepatitis C, and the tone that the Society has adopted	20
21	from time to time over the years.	21
22	The Society is aware that there is some dismay about	22
23	the position it took in relation to litigation over HIV	23
24	infections and its communication to Government of its	24
25	stance. The documents indicated that when it first	25
	45	
1	moral not legal grounds, and that was an unusual tactic	1
2	driven by necessity. The Society had had advice from	2
3	a barrister that any claim it brought on behalf of the	3
4	charity was unlikely to succeed and, in addition, money	4
5	was needed within the timescales of the dying, not	5
6	within the timescales of litigation. That would take	6
7	years, which people didn't have.	3 7
8	Convincing Government to take this unusual moral	8
9	case seriously required an explanation of both reasons	9
10	as to why litigation was not an option. After the	10
11	Macfarlane £10 million had been secured, the Society	11
12	pressed on with a second campaign for the same reason:	12
13	that infected people needed money urgently. The Society	13
14	notes the witness statement of Lord Frank Field who	14
15	wrote to you of his own volition, in which he described	15
16	his work with David Watters to get adequate compensation	16
17	for infected haemophiliacs so they didn't have to start	17
18	court action, and the media campaign they collaborated	18
19	on with the Sunday Times.	19
20	In November 1989, the Government offered a further	20
21	£24 million, including payments of £20,000 each to each	21
22	person infected or their family of those who had died.	22

1	asked the Government for financial help for people with
2	haemophilia infected with AIDS, the Government's
3	response was that it only pays compensation where there
4	is fault, and it therefore invited infected people with
5	haemophilia to sue. That's there in a document,
6	HSOC0003459, and I'll come on later in these submissions
7	to talk about the Government's response to people who
8	have been affected by some of the Cumberlege medicines
9	and devices, particularly those affected by mesh and
10	sodium valproate, which has been exactly the same. That
11	might be good evidence, you might think, that that was
12	the Government's response in the 1980s, since that
13	remains the Government's response in the 2020s.
14	Litigation was only open to those who had Legal Aid
15	or enough money to pay lawyers, and that left many
16	people with haemophilia in the middle. They didn't have
17	insufficient money to qualify for Legal Aid and they
18	didn't have enough money to pay privately for
19	representation, so they couldn't bring a claim. The
20	Society was painfully aware that people were dying and
21	it didn't want to use what little energy and time they
22	had left on legal proceedings, so the Society's aim was
23	to get something for everyone infected as quickly as
24	possible.
25	To do that, it pursued a campaign and later ones on 46

recalls in his statement being "knocked over by the violence of the language used".

At that point, over 100 people had died of infected blood products and the litigation wasn't scheduled to start until 1991, by which time many more would have died.

After the award of the ex gratia payment, the number of claimants into the litigation increased because many people used all or some of their £20,000 payment to fund joining the litigation. So the Society launched another media offensive for out-of-court compensation, and it did so despite Dr Kernoff, who was sitting on its Medical Advisory Panel, advising the Society against becoming involved on the grounds that "People might start suggesting that people with haemophilia are too greedy". The reference for that is HSOC0010954. As you know, settlement of the court action was reaching after Mr Justice Ognall's intervention in June 1990 where he repeatedly referred to a moral duty. Much later, in June 2018 -- I think that must be 2008 -- Mr Graham Ross, the solicitor who acted for very many of the claimants, appeared before the Archer 23 Inquiry, and he explained how the settlement had been 24 achieved at some length. In his evidence, he appeared appreciative of the Society's efforts to assist the 25

48

There was pressure exerted by MPs acting on behalf of

the Government at an all-party meeting on 30 November

1989 to compel acceptance of that offer, and Lord Field

23

24

1	litigation, and the Society notes the statement of Sir	1	charity. Those running it were exhausted by campaigning
2	Rupert Jackson, who was then junior counsel for the	2	and the organisation was on the brink of bankruptcy.
3	claimants in the litigation. He says that the case was	3	Some of the trustees felt that the Society wasn't
4	very worrying, that plaintiffs were dying every month,	4	representing them and they'd achieve more from the
5	that by the time of the settlement 148 patients had	5	outside than they could from the inside and they set up
6	died, and the case "faced significant difficulties on	6	their own campaigns.
7	liability and causation".	7	The documents referred to by Ms Burt show that there
8	He described the central defendants as	8	was a considerable amount of working together, but
9	"intransigent", and said in his view "It is unfortunate	9	there's no doubt that these splits were painful and sad.
10	that the Government of the day did not face up to its	10	Everybody wanted the same thing, but it may be that the
11	moral responsibility in the same way that the present	11	combined effect of different tactics taken by different
12	Government has", at which point, after yesterday, we	12	campaigners was greater than one single campaign would
13	might say "up to a point, Lord Cooper".	13	have been. The Society felt it had a responsibility to
14	Turning to hepatitis C. The Society is painfully	14	the whole of the bleeding disorder community, and one
15	aware that there are a number of infected and affected	15	can see that in its attempts to meet everyone's needs,
16	people who feel that it did too little too late and it	16	thereby perhaps pleasing nobody and dissatisfying
17	wasn't there for the community at a time of need. The	17	a cross-section of the membership.
18	Society has done its best to respond to those concerns	18	If we look briefly at a page from the 1998 Bulletin,
19	in two very lengthy witness statements made by its	19	WITN6392059 at page 10.
20	current chief executive, Kate Burt. I think only one of	20	Squidgy print, which I hope you can read.
21	them has just been made available.	21	This is a letters page.
22	As she says in those statements, the Society hears	22	Lawrence, I don't know if you can just put the whole
23	you, deeply regrets that you feel let down and would	23	page on so that people can see what it there, it
24	welcome the opportunity to listen to those who feel	24	looks like that.
25	harmed. The mid-'90s were a time of crisis for the 49	25	It's printing three letters which are a response to 50
1	the chair of the Hampshire Group. If we look at the top	1	response and, for those with particular needs and
2	left, this is from Stan Cockburn, the chair of the Manor	2	infections, an unreasonable one. It's the Society
3	House Group. And the writer of the article that these	3	trying to please all of the people all of the time and
4	letters are responding to is Mary Clarke. And he says:	4	failing to do so.
5	"She is concerned that the Society will divide into	5	Then we've got another letter if we look at the
6	different groups. I must ask, is she living in the	6	bottom of the left-hand column:
7	clouds? The Society is already split into several	7	"Wake up, Mrs Clarke. The haemophilia community ha
8	groups: we have haemophiliacs who have received a very	8	been divided ever since some people receive viral
9	derisory payment for being infected with HIV. We have	9	infections through their contaminated treatment. We
10	young people who will be receiving recombinant products	10	shall continue to be divided until we can secure safe
11	now coming on line, as they should. What have the	11	treatment for all and until there is some recognition by
12	people of my own generation been given? Absolutely	12	the Government that they have a moral obligation to us."
13	nothing."	13	Then at the end of this letter:
14	And in the last paragraph of that letter:	14	"There have been far too many mistakes made at the
15	" [the] Editorial stated that the HCV campaign	15	expense of haemophiliacs and we need to shout about it."
16	has highlighted the need for better treatment for	16	I'll say some more about the Society's campaigning
17	hepatitis patients. This lesson should have been learnt	17	tone in a moment.
18	from the HIV campaign and not as an afterthought."	18	And lastly, you get a letter from a different
19	The editor's reply is:	19	perspective.
20	"We need to help everyone with haemophilia. All	20	"I have been married for 30 years to a man with
21	those I speak to agree that we must continue the HCV	21	haemophilia. [He] is now 63 and one of the few
22	campaign and we shall. However, I would like to see all	22	haemophiliacs who did not contract HIV. He has now been
23	of us helping each other and not just following our own	23	told he is [hepatitis C] positive I feel this letter
24	particular needs."	24	from Mary Clarke points to the fact that people like
25	I think you can see how that is both a reasonable	25	[him] have been forgotten. We feel guilty that he ONLY
	51		52

1	ouffere ee far frem bloode "
1 2	suffers so far from bleeds."
2	And in the last paragraph: "There must be many other haemophiliacs like
4	
4 5	<i>(redacted)</i> , who feel they cannot approach the Society because they only have haemophilia."
6	
7	Thank you, Lawrence. SIR BRIAN LANGSTAFF: Just one moment. I wonder if we can
7 8	redact the name there.
9	Thank you.
10	MS GOLLOP: The fact that people felt they had to leave the
11	Society remains a source of great regret to the charity
12	now. This hurt, and everyone involved in these splits
13	was hurt, were a consequence of Government forcing
14	physically injured and psychologically damaged and
15	bereaved people to fight for justice and compensation,
16	and it is partly these experiences in the 1990s that
17	causes the Society to now advocate strongly for a system
18	based on swift and fair redress for NHS patients who
19	suffer avoidable harm from a system's breakdown.
20	Lastly, something about saying it right.
21	The Society recognises that there are some people
22	who feel that it hasn't been vocal or hard hitting
23	enough in speaking truth to power, and has, in summary,
24	been too deferential. Its focus on achieving the
25	greatest good for the greatest possible number has
	53
1	wrote a letter of complaint with, it seems, the
2	knowledge of some members of the Civil Service, and
3	a complaint was made and upheld to the advertising
4	standards board.
5	All of that said, generally, the Society has had
6	most campaigning success when appealing to the
7	Government's moral, not legal duty. And the Carpet of
8	Lilies campaign, which witnesses have said they found
9	moving, relied on personal accounts of the damage done
10	to individual lives when Government loses sight of its
11	moral obligation to keep a section of the public safe,
12	and that was a powerful campaign.
13	There is some evidence that a quiet explanation of
14	
	a situation can be more effective than a loud one.
15	a situation can be more effective than a loud one. Mr Roger Moore told the Inquiry on 18 January last year
15	Mr Roger Moore told the Inquiry on 18 January last year
15 16	Mr Roger Moore told the Inquiry on 18 January last year that when the Society delegation, which included the
15 16 17	Mr Roger Moore told the Inquiry on 18 January last year that when the Society delegation, which included the three young men with haemophilia infected with HIV came
15 16 17 18	Mr Roger Moore told the Inquiry on 18 January last year that when the Society delegation, which included the three young men with haemophilia infected with HIV came to ask the Minister for money, and that was a meeting
15 16 17 18 19	Mr Roger Moore told the Inquiry on 18 January last year that when the Society delegation, which included the three young men with haemophilia infected with HIV came to ask the Minister for money, and that was a meeting that the Minister went into firmly decided that no money
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1	caused it to take a pragmatic approach and to be an
2	organisation, so far as it could, that Government could
3	do business with, when it was possible to do business.
4	The brief account of the campaigning work that the
5	Society did between 1987 and '91 to obtain some
6	financial redress for all people with haemophilia
7	infected with HIV as soon as possible illustrates, we
8	submit, how tenacious the Society was and how it didn't
9	bow to pressure but kept on campaigning for more after
10	the £20,000 lump sums were paid. And it was capable of
11	hard-hitting tactics at times. For example, when
12	campaigning for the out-of-court settlement in 1990 it
13	ran an ad campaign. We've not been able to find
14	a picture of this, but there is a description of it in
15	the letter of complaint that was written about the ad
16	campaign to, I think, the BMJ. And this is a new
17	document that's been given the number HSOC0029910.
18	It had a picture of a child, and the caption read:
19	"Heredity gave him haemophilia, then the NHS gave
20	him AIDS."
21	But there was a complaint about that, and I think,
22	trying to piece it out, the essence of the complaint was
23	that ad campaign ran in 1990 and people looking at it
24	might think that the NHS was giving children AIDS in
25	1990 rather than in the 1980s. In any event, a Dr Bird
	54
1	The Trust and schemes were never adequate, fair or
2	dignified, but they were the best that the Society would
3	achieve in the face of Government refusal to compensate
4	people for their injuries. And the Society's efforts on
5	behalf of the whole community meant that many people who
6	would not otherwise have done so did at least get
7	something in their lifetime, even though it was not
8	enough.
9	That brings me to the present. And to an apology.
10	In 2017, the Society issued an apology as follows:
11	for its statements during the 1980s, reassuring patients
12	that new factor treatments were safe and to continue
13	using them.
14	"We also lobbied the Government to continue allowing
15	the import of products from the USA.
16	"The advice we gave our members was based on
17	guidance from the Haemophilia Centre Directors (now
18	known as the UKHCDO) and from the Government. The
19	leadership and trustees of The Haemophilia Society were
20	misled and, as a result, unwittingly further contributed
21	to the Scandal.
22	"However, we accept that our actions and statements
23	at the time, while well-intentioned and based on expert
24	advice, have subsequently been shown to be damaging to
05	

25 the community and false. For this, we unreservedly

1	apologise."	1
2	The submissions of some other infected and affected	2
3	Core Participants make it clear that some people feel	3
4	that does not go far enough.	4
5	Now, there's a risk that the Society will sound like the DHSC, and I hope you won't take what I'm now going	5 6
6 7	to say in that same way. The point of the Inquiry for	0 7
	the Society is multiple, but one of the points is to	8
8 9	listen to Sir Brian's objective and fully informed	8 9
10	judgment, and that will be an important part of the	9 10
11	learning it does about itself in the past and now.	10
12	The Society thinks that it makes sense to reflect on	12
13	his findings before it says any more than it said in	12
14	2017. It will then have the benefit of something that	13
15	is considered and not the Society marking its own	15
16	homework, but listening to a proper examiner and	16
17	a thoughtful dissection of what it got right and what it	17
18	got wrong.	18
19	The Society said this in its written submissions:	19
20	that it would like to say to the Inquiry and to each	20
21	person infected and affected by contaminated blood that	21
22	it was not separate to its members. It was its members.	22
23	It was run by patients for patients. Those who formed	23
24	the Executive Committee were individuals who shared with	24
25	the members they served the same group of doctors and	25
	57	
1	Society hopes that this period of time between now and	1
2	the report's publication and the setting up of the	2
3	compensation framework and the legal and psychological	3
4	support structures that need to accompany it could be	4
5	a time of healing.	5
6	It would like to pay tribute to the infected blood	6
7	campaigners who have given such a large part of their	7
8	lives up to the fight for justice. These include the	8
9	Manor House Group, the Birchgrove Group, Tainted Blood,	9
10	the contaminated blood campaign, positive women,	10
11	Haemophilia Action UK, Haemophilia Scotland, Haemophilia	11
12	Wales, the Scottish Infected Blood Forum, Haemophilia	12
13	Northern Ireland, Friends and Families of Haemophilia	13
14	Northern Ireland, the Fatherless Generation and	14
15	Factor 8, alongside many other groups and charities and	15
16	individuals without whom we would never have seen this	16
17	Inquiry take place.	17
18	We particularly remember those campaigners who did	18
19	not live to see the end of the Inquiry. Thank you.	19
20	We turn lastly to the future and to recommendations.	20
21	We've covered these extensively in written submissions	21
22	and I've got written down on paper in front of me	22
23	a number of lists.	23
24	I will summarise things as briefly as I can but our	24
25	submissions were supported by the results of a survey of 59	25
	00	

1	such information, advice, choices and treatments as were
2	made available to them all. They suffered or watched
3	the children they loved suffer the same appalling
4	treatment-induced illnesses and deaths and the Society
5	doesn't seek not to be judged. It does seek to be
6	judged in this light.
7	Throughout the Inquiry, the Society and its trustees
8	and staff, many of whom are here today, have made it
9	their mission to listen and build bridges while
10	remaining sensitive to those who need distance from it.
11	That any member of the bleeding disorder community
12	should need such distance remains a source of profound
13	sadness to the Society, and it hopes to be able to
14	rebuild trust and work together in the future. The
15	Society would encourage anyone who has not had the
16	opportunity to do so to look at Kate Burt's statements,
17	and those add to the statements made by others who have
18	provided evidence to the Society.
19	On behalf of everyone at the charity, Clive Smith,
20	who you know and who is here, and Kate Burt, who you may
21	not know but who is also here please do go and say
22	hello. Kate, perhaps you'd like to put your hand in the
23	air.
24	We hear you and we invite you and hope you will feel
25	able to talk to us or continue to talk to us. The
	58
1	the membership and their priorities and needs. One of
2	the things that those responding to the Society's survey
3	were clear about and I think this is something that
4	everybody here will share is the fact that they were
5	very clear that annual payments must continue. The
6	Society was pleased to see that Sir Robert's report is
7	called Compensation and Redress for the Victims of
8	Infected Blood. It agrees with Mr Snowden that language
9	is important. Use of words such as "hardship" and
10	"recompense", and so on, have led to confusion about the
11	purpose of monies made available, restrictions on
12	payments out, and the widespread feeling among
13	applicants that they have had to beg for scraps.
4.4	It is appropriate for the new financial neumants

It is appropriate for the new financial payments, which will be made as a result of this financial Inquiry, to be called what they are: compensation. The Society repeats what it's called for in submission to any compensation scheme that's established and here comes the list:

Anyone who has been significantly affected, havingthe right to make a claim;

To continue existing support schemes alongside

a compensation scheme;

Compensation to be sufficiently personalised to

ensure it reflects the loss and damage served by

4		4	
1	an individual with a framework that should include set	1	compensation package, such as psychological support,
2	tariffs to allow a faster but robust system for those	2	health passporting and Government underwritten life
3	who want to take that route;	3	insurance;
4	A fast track to an emergency payment for those in	4	Financial advice available to all receiving
5	urgent need;	5	compensation;
6 7	An upfront lump sum to be paid to the infected and	6 7	An individual assessment by a judge-led panel with
8	affected community in advance of the full amount; A clear, straightforward process which is easy to	8	representation from the community, if people choose that
0 9		8 9	route; and To widen eligibility to include impact from viruses
9 10	use; Specialist support for people making applications,	9 10	or exposure outside the current support schemes, such a
11	particularly where evidence has been lost or destroyed;	10	hepatitis B and vCJD.
12	The claims should be approved on the balance of	11	Accessibility. A significant number of eligible
12	probabilities with the starting point being that the	12	Society members are older. They don't have smartphone
14		13	
14	evidence of the applicant is believed; total parity across devolved nations;	14	They don't have tablets or computers, they prefer to get information on paper in the post and they are
16	A compensation package funded by the Westminster	16	traumatised by their infections. They've had to fill
17	Government because this scandal happened before	10	these forms out time and again and they can't face the
18	devolution;	17	idea that they'll have to do it once more. They don't
19	A system which allows transfer of information from	10	want to have to handle any more administrative tasks
20	supported administrators to schemes to reduce the burden	20	themselves. They need help.
20	on claimants to provide information;	20	The Inquiry has heard a substantial body of evidence
21	A transparent appeal system;	21	about the hurt caused by the administration of the
22	Previous payments not to be taken into	22	schemes, the future arrangements must be characterised
23	consideration;	23	by respect and compassion.
24	Inclusion of non-financial elements in the	24	UK support sorry, the Society supports the
25	61	23	62
1	submission by the UKHCDO at paragraph 262 of its closing	1	access to current treatment and up-to-date information,
2	submissions about compensation for those who have	2	ongoing longer term assistance, research on future care
3	cleared infection with hepatitis C spontaneously.	3	and palliative care, training and education, education
4	Psychological support. The publication of the	4	about the scandal itself and an apology and a memorial.
5	Inquiry's report will be the start of a new chapter and	5	We repeat all of those and, today, we wish to say
6	the risk that vulnerable individuals will be left to	6	a little more about treatment and information for the
7	cope alone again. That mustn't be allowed to happen.	7	bleeding disorder community, and something about public
8	It is unfortunate that the start of the new framework	8	inquiry reform, redress, consent and candour. Before
9	will come at a time when the country's finances are in	9	turning to those areas, a word about follow-up and
10	poor shape and public sector workers are on strike. The	10	delivery.
11	Society hopes that the Inquiry will make it clear that	11	At the beginning of these submissions, I spoke about
12	one of the lessons to be learned from the contaminated	12	the need for a formal framework to ensure that the
13	blood scandal is that denial of injustice and	13	Government's feet are held to the fire. The Patient
14	postponement of financial responsibility while	14	Safety Commissioner Dr Hughes has said that her motto
15	generations suffer is a false economy. Late	15	"Speak up, listen up, follow up". It may be that for

ing of these submissions, I spoke about mal framework to ensure that the et are held to the fire. The Patient oner Dr Hughes has said that her motto is 'Speak up, listen up, follow up". It may be that for 15 16 matters within her remit, it could be appropriate to 17 recommend that she be entrusted with the work of 18 following up delivery, perhaps including regular 19 progress reports. Alternative mechanisms include 20 adjourning the Inquiry, post-publication of the report, 21 with the recommendation that the chair review 22 implementation of accepted recommendations within 23 a given time period, and the possibility of 24 a supplemental report commenting on the success or 25 otherwise of the implementation in the interim, plus or

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Non-financial recommendations. In common with many

compensation costs more than timely and adequate redress

when people are ill and dying, and carers and dependants

are most in need of the money, and the Society hopes,

Sir Brian, that you might be able to get across the very

recommendations on public inquiry reform, redress for

recommendation implementation, the Irish experience,

of the other Core Participants, the Society made

avoidable harm, consent, continuing scrutiny of

simple message: delay doesn't pay.

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1	minus a recommendation that the implementation of	1	consultants.
2	recommendations in the final report be reviewed by the	2	Peer review has identified a persistent lack of
3	Cross-Party Health and Social Care Committee on	3	a full compliment of multi-disciplinary team members
4	a regular basis with consequent reports to Parliament.	4	that has gone uncorrected, despite having been
5	This appears to be what is happening in relation to	5	identified by previous peer review reports. These
6	follow-up of Cumberlege, and when I'm not pinging her	6	deficiencies ultimately arise from inadequate funding of
3 7	about Woman's Hour, I like to ping Ms Richards with	7	Haemophilia Centre infrastructure.
8	entertaining videos of the Select Committee in progress.	8	It would be nice, at a minimum, for your care to be
9	It's her choice as to which she prefers.	9	properly funded.
10	Given the work that Dr Hughes has said she will be	10	The Irish experience. Brian O'Mahony told this
10	doing to follow up redress for those affected by the	10	Inquiry that after compensation, the Health Amendment
12	Cumberlege Review Medicines and Devices, the Society	12	Act card, and knowledgeable, compassionate liaison
12	hopes it may be possible for this Inquiry to liaise with	13	officers or case managers were the recommendations that
13	her about what, if any, infected blood matters may fall	14	have proved most valuable over time, as infected people
15	within her remit.	15	age and their needs change. That experience should
16	Access to current treatment and up-to-date	16	inform, we suggest, the package of measures put into
10	information. The Society endorses paragraph 264 of the	10	place to support the future welfare of infected and
17	UKHCDO closing submissions, and those are about	18	affected people.
18 19	provision of comprehensive care, including a core team	10	We ask you to make a recommendation that all those
19 20		20	infected by blood and blood products and all people with
	of physicians, clinical nurse specialists,		
21 22	psychologists, physiotherapists, lab scientists and	21 22	a bleeding disorder have access to information relevant to them about their condition and new treatments to be
22	social workers I'm quoting from their submissions	22	
	now and other experts who address disease related to	23	provided through haemophilia centres; guaranteed access
24 25	issues and complications, including hepatologist		to recombinant you may be surprised to hear that
25	obstetricians, gynaecologists, orthopaedic and dental 65	25	there are still some rare bleeding disorders where 66
1	people are reliant on treatment made from human blood	1	In November last year, it was told about an embalmer who
2	and not synthetic treatments a choice of treatment to	2	last year refused the touch the body of a man with
3	suit lifestyle; and guaranteed access to new therapies	3	von Willebrand's disease who was thought to have been
4	including gene therapy; guaranteed access to	4	infected by blood and had cleared the virus many years
5	a multi-disciplinary care package, including	5	before he died last year.
6	psychological services, pain management and	6	I'm very grateful to the research that's done by the
7	physiotherapy; and a quality of access to care including	7	Leigh Day team. They have uncovered relevant 2018
8	dental treatment and, specifically, endoscopies.	8	Health and Safety Executive regulations and it would
9	The Society does not ask for its members or for the	9	seem, from this 2022 experience, that those are not as
10	community the ability to queue jump. It does ask for	10	widely known about as they should be.
11	a recommendation for a health passport that helps the	11	I am hopeful that Ms Scolding and her solicitors
12	infected and affected communicate their history and	12	will have more to say about this in due course and
13	their needs quickly, so that they can get the help that	13	I will leave this issue to them.
14	they need effectively, without having to go through the	10	Turning to public inquiry reform. There's no test
15	whole story from start to finish.	15	for deciding when a public inquiry should be held.
16	In its written submissions, the Society asks for	16	Alan Milburn described the current framework as "pretty
17	recommendations on longer term assistance, research on	10	non-existent or woolly". Successive ministers' denial
18	future care and palliative care, training and education,	18	of requests for a public inquiry were based on their
10	and an apology and memorial. I'm not going to consider	10	acceptance of the line they were given by the civil
20	those now but they're of equal importance to things I am	20	servants who were supposed to be helping them, that
20	talking about, and we commend those submissions to you.	20	there was no negligence. And that was even when one
21	On a separate topic, and I shared this information	21	minister, Caroline Flint, was in receipt of
22	with Ms Richards and Ms Scolding, King's Counsel,	22	correspondence from the Society that spelt out the fact
23 24	yesterday, the Society has very recently received	23	that patients had been treated without their consent and
	yoolorady, the boolety has very lebelluly lebelved	27	
		25	experimented upon. Further, that nationts were given
25	information about hepatitis C and funeral arrangements. 67	25	experimented upon. Further, that patients were given 68

1	the best treatment available, and anyway, even if they
2	hadn't, all the lessons had been learned.
3	The history of inadequate co-operation with Archer,
4	the defensive, insufficiently objective self-sufficiency
5	report, and the delay in setting up this Inquiry are all
6	evidence that a clear and transparent mechanism for
7	making decisions about when to hold a public inquiry, or
8	a non-statutory review, would be extremely helpful if
9	not required. The Society suggests a recommendation is
10	made that there be an independent body with the power to
11	convene a public inquiry that would require an
12	amendment to the Inquiries Act or a recommendation to
13	the relevant minister that a public inquiry be held.
14	Such an independent body could be charged with
15	applying transparent criteria to assess the
16	circumstances in which inquiries or reviews must be
17	held. And it could collate them so that there's
18	a central repository of recommendations, monitor which
19	recommendations are accepted by Government and how the
20	implementation works out, and, in appropriate
21	circumstances, require inquiry chairs to review such
22	implementation as there has been.
23	The Society also feels that there is a specific need
24	to say something about a requirement that the
25	decision-maker meets victims in person.
	69
1	advocates for a move from our current adversarial system

2 of negligence, where the burden is on you, the infected 3 or injured person, to prove not only that something went 4 wrong but that the injury you've suffered was caused by 5 what went wrong, and a switch from that to a no-fault 6 system, or one of redress for avoidable harm caused by 7 systems failure.

8 First Do No Harm considered the three medical 9 devices and medicines we've looked at. And on the face 10 of it, they have no connection to blood. But her 11 observations about candour, patient safety, redress and 12 the need for a cultural shift in the NHS are highly 13 relevant. She explained in her report that the duty of 14 candour appears not to have had the desired effect of 15 increasing reporting and disclosure, and we draw the 16 Inquiry's attention to paragraphs 2.47 to 2.51 of her 17 report. 18 In 2.51 she said this:

19 "We believe that a cultural shift away from blame is 20 needed to create a healthcare system where people are 21 open and honest. We outline how we feel a no-blame, 22 systems-based approach to delivering redress as 23 a substitute for litigation could drive this shift in 24 paragraphs 2.37 to 2.39 (... [and] Appendix 3). We believe this shift is essential to deliver a safer NHS 25 71

1 Sir, you've heard evidence from Mr Burnham and 2 Mr Jeremy Hunt that both were actively counselled by 3 civil servants against meeting in person those who were 4 campaigning for public inquiries. You'll remember 5 I think -- I think it was Mr Hunt said he'd been 6 counselled against meeting Nazanin Zaghari-Ratcliffe. 7 The Society considers that this sort of a meeting is 8 essential. You've heard at least three examples of 9 individuals being profoundly moved and having their 10 views changed by meeting infected and affected people: 11 John Moore, who we've already discussed, in 1977; 12 Mr Hunt in his interaction with Mr Dorricott and his 13 family; Andy Burnham meeting Eleanor and Fred Bates and realising that something was very wrong. There's no 14 15 substitute for the decision-maker hearing in person from 16 those who are suffering and seeking justice. There 17 shouldn't be a filtering by civil servants. 18 It submits that however decisions about whether to 19 hold or not hold a public inquiry or statutory review 20 are made in future, an in-person meeting should be 21 a mandatory part of the decision-making process. 22 Candour, redress and consent. These three 23 overlapping concepts, which together form a virtuous 24 circle, if you remove any one of them, the circle 25 collapses. Jeremy Hunt and Baroness Cumberlege are 70

1	where healthcare professionals have no reason to fear
2	being candid and telling the truth to their patients."
3	Her solution was a redress agency: a non-adversarial
4	process with determinations based on avoidable harm,
5	looking at systemic failings.
6	The Government rejected that recommendation
7	outright. Its July 2021 response to her report was that
8	those suffering from sodium valproate and pelvic mesh
9	wanting compensation would have to bring legal
10	proceedings. Exactly the same response it gave to you
11	over AIDS in the 1980s and over hepatitis C in the
12	1990s.
13	One of the reasons it rejected the recommendation
14	was, said the Government, that it already has the
15	ability to set up support schemes. And the best example
16	that it could come up with was the this is how it
17	phrases it "infected blood support scheme". The only
18	inference that we can draw from the Government's
19	reference to that and we assume that that is
20	a reference to EIBSS, and this is a reliance in
21	July 2021 on EIBSS as some sort of model of good
22	practice is that the Government actually thinks that
23	the infected blood support schemes provided or provide
24	an example of redress done well, so that we don't need
25	to change anything.

1	That suggestion flies in the face of all the	1	no reference to that a couple of months later when the
2	evidence heard in this Inquiry by those of you who	2	Government responded to Cumberlege in July.
3	utilise the schemes. It suggests that the Government	3	The Government has set up two litigation gateways
4	doesn't know about or hasn't been listening to the	4	for those harmed by the medicines and devices that
5	evidence of users given to this Inquiry. You've	5	Baroness Cumberlege looked at. You can go down the
6	provided abundant evidence of the adverse effect on you	6	normal route where you instruct your own lawyers, and
7	of the lack of any financial assessment of your losses	7	they get on with the business of litigating.
8	and needs, psychological harm caused by different	8	Alternatively, you can ask the Government to
9	treatment of the infected and affected in the devolved	9	investigate, and this is what happens. The Government's
10	nations, divisive means testing, needless complexity and	10	solicitors will provide the Government with a report.
11	opacity, applications being dealt with and basic errors	11	The Government will look at its own report, and it will
12	being made or applicants being disbelieved, onerous	12	either admit liability and pay compensation to you, or
13	requirements for evidence, unexplained exclusion of	13	it will deny liability. Either way the Government will
14	bereaved parents, the lack of any proper voice of the	14	not release its report to you, and you can see these
15	infected and affected within the administration, and the	15	gateways set out on a web page
16	conflict between users in dire need and administrators	16	resolution.nhs.uk/vaginalmesh.
17	who hold back large reserves of monies intended to be	17	That approach is consistent with an adversarial
18	paid out.	18	system in which each side can claim privilege and
19	Second, the Government's July 2021 response failed	19	withhold the expert advice it's received. It's a legal
20	to acknowledge or even refer to the oral evidence of	20	process geared towards establishing blame, not an open
20	Mr Hancock. He gave evidence to the Inquiry on	20	and transparent patient safety driven process aimed at
22	21 May 2021, and he accepted that the trusts and schemes	22	establishing the harm that's been caused, how it could
23	had been run without there being "a proper process	23	have been avoided, and what needs to change.
23	around coming to a fair and just way of ensuring that	23	And you have to wonder, where the report obtained by
25	people are supported", so it's surprising that there's	25	Government through its alternative litigation gateway
20	73	20	74
1	tells the Government that it needs to admit liability	1	others in future, because there would be well-run
2	and pay compensation, why should not the person who has	2	schemes that could be adapted quickly to suit the needs
3	been harmed by its negligence see that report? One	3	of different groups of people avoidably injured by
4	answer could be a concern by Government that that	4	systems failures.
5	individual might then share that report with other	5	Consent. The Cumberlege Review's findings
6	injured patients.	6	demonstrate that there's still quite a lot going wrong.
7	So this is not a system for learning; it's a system	7	Doctors are too ready, still, to make assumptions about
8	for being defensive.	8	what patients want, or adopt the position that they know
9	There are signs that the Government may be having	9	what is in their patients' best interests. They're
10	a change of heart. In this Woman's Hour interview on	10	still overselling benefits, underselling burdens, and
11	3 January, Dr Hughes told the BBC that the Health	11	not being clear enough about that which is uncertain and
12	Minister has asked her to look into redress for the	12	that which is unknown. They're particularly bad about
13	Cumberlege victims, if I call them that, and Dr Hughes	13	giving balanced advice about medical products where
14	is looking for a commitment from the Government that it	14	there's no consensus about the risks, and therefore no
15	will provide that redress. One didn't get the	15	consensus about how you should weigh up the benefits and
16	impression that she'd had the answer she was looking for	16	burdens.
17	at that stage.	17	The Society notes, for example, paragraph 5.41 of
18	But these patients shouldn't have to fight the NHS	18	First Do No Harm. That records that as late as 2014,
19	and the Government any more than you should have to.	19	the MHRA was maintaining in a report it produced at the
20	A fair, predictable, swiftly responsible system for	20	request of the Chief Medical Officer that the benefits
21	redress is an idea whose time has come. And a further	21	of mesh outweighed the risks. The Cumberlege Review
22	advantage is that it could be a Centre of Excellence for	22	found that that stance did not fully reflect an
23	financial redress frameworks. The delay that you are	23	understanding of all the risks, and it affirmed the
24	enduring while the cross party working group responds to	24	evidence of one campaigner that "the real world evidence
25	Sir Robert's detailed scheme could be minimised for 75	25	and patient stories of harms have been overlooked". 76

1	The Society invites you, sir, to consider the	1	tha
2	informed consent section of the Government's response to	2	
3	that review and consider whether its actions for	3	de
4	improvement go far enough.	4	sa
5	Publication of this Inquiry's report might also	5	he
6	provide an opportunity to recommend ongoing monitoring	6	as
7	of implementation of, for example, the National	7	his
8	Institute for Health and Care Excellence's shared	8	CO
9	decision making guideline, and importantly, the extent	9	the
10	to which patients are routinely made aware that they	10	to
11	have the right to record a discussion with a doctor if	11	for
12	they wish to do so, and the extent to which patients are	12	sei
13	taking up that opportunity and measure the effect.	13	
14	A study on those matters could be beneficial.	14	am
15	The Civil Service. A few words about the	15	fou
16	Civil Service, which has not been an ally to those	16	he
17	harmed by infected blood in your search for truth. We'd	17	
18	like to say an extended bit, if we might, about the	18	rec
19	Government's 2006 self-sufficiency report.	19	аc
20	The Society has been dismayed to read the statement	20	do
21	of Peter Burgin, the author of the Government	21	tha
22	self-sufficiency report the original author, I should	22	up
23	say and his statement is dated 15 December 2022.	23	ref
24	Since it was made available the day before written	24	ba
25	submissions were due to be filed, it wasn't a matter	25	alle
	77		
1	added without his knowledge.	1	co
2	So far as the Society can see we could be wrong	2	of
3	but don't think so Mr Burgin's statement to this	3	ag
4	Inquiry is the first time that the then professor	4	So
5	Frank Hill is identified as a contributor to his work.	5	
6	There are footnotes referring to Mr Burgin's interview	6	lt v
7	with Chris Hodgson and his interview with Dr Mark	7	tha
8	Winter, and there is a reference to reports from	8	Mr
9	Dr Hill, but no mention of an interview with him. We	9	it n
10	assume, but we don't know, that when Mr Burgin	10	Mr
11	approached Dr Hill to assist with the self-sufficiency	11	CO
12	report, Dr Hill did not disclose to him the fact that	12	as
13	a negligence claim brought on behalf of one of his child	13	like
14	patients, whom he had infected with HIV through	14	he
15	contraindicated prescription of Factor VIII rather than	15	
16	cryoprecipitate, had been settled at trial in 1992.	16	Pro
17	Had the published self-sufficiency report included	17	cha
18	a list of contributors, the Buggins family, and perhaps	18	ev
19	the Society, would have had additional grounds to	19	oth
20	challenge it. Had Dr Hill learned any lessons from the	20	tha
21	case brought against him and had he been open and honest	21	
22	with Mr Burgin, Mr Burgin would have been given direct	22	inte
23	evidence that at least one cohort of child patients may	23	He
24	not have been given the best treatment available at the	24	wa
25	time but, instead, it was possible for Professor Hill to	25	
	79		

1	that we were able to deal with in written submissions.
-	
2	This is the story. He completed his report and
3	delivered the final draft on Christmas Eve 2002. He
4	says in his statement that in preparation for his report
5	he had a meeting with the Society, and he describes that
6	as having been extremely helpful. After he delivered
7	his report, the Department of Health paid some
8	consultants we don't know who or very much about
9	them to amend the report. The amended draft was sent
0	to clinicians and others again, we're not sure who
1	for their comments prior to publication. It was not
2	sent to the Society prior to publication.
3	The Department published the report which it had had
4	amended without telling Mr Burgin, and Mr Burgin only
15	found out that the report, the original version of which
6	he drafted in 2002, had been published in 2018.
17	If you look at his witness statement, which I'll
8	recommend, WITN7485001, he provides a table with
9	a comparison of what he wrote in 2002, and the amended
20	document was published in 2006. That effectively shows
21	that his report was, to use the modern expression, sexed
22	up by the consultants employed by the Government. The
23	references to the Society appealing to Government not to
24	ban imports of American imported product despite
25	allegedly knowing of the risk of NANB hepatitis were
	78

	cover up his wrongdoing and mislead the original author
2	of the Government's own internal review and, I say
3	again, an internal review that it did not share with the
Ļ	Society in draft before publishing it.
5	Importantly, we also see history repeating itself.
6	It was through the good offices of Elisabeth Buggins
,	that it was drawn to my attention why it is likely that
3	Mr Burgin went to Professor Hill. We don't know and so
)	it may be that you wish to ask Mr Burgin, I don't know.
0	Mr Kennedy, King's Counsel, has been kind enough to
1	confirm the facts for me, but in 2002, Professor Hill,
2	as he then was, was the chair of the UKHCDO, so it seems
3	likely that he was interviewed in his capacity as the
4	head of that organisation.
5	One sees alarming parallels with what happened with
6	Professor Bloom, who, as a result of being perhaps the
7	chair of the UKHCDO, was then asked to sit on almost
8	every other committee and had a finger in almost every
9	other blood products pie, and we see the damage that

that overreliance on one single individual caused. It's a pity that there wasn't a wider breadth of interviewees, perhaps. It is no fault of Mr Burgin's. He did the best that he could in the circumstances and was not to know otherwise.

The whole history of that report, its amendment, its 80

 promotion of the communit of the communit of control in a community of the community in the community into community in the community into community in the community into c	1	publication without any consultation with those who'd	1	Mr Burgin's witness statement, makes the following
 correct inaccurates, is a good illustration of what can happen when there is no enforceable duty or oxidi servants to balave with candour, generas and transparency. There's no incertive for patient groups contributed, there should be allow of control torse. and transparency. There's no incertive for patient groups contributed, there should be allow of control torse. and transparency. There's no incertive for patient groups control servants to balave with candour, generas and transparency. There's no incertive for patient groups control servants and not engage. transparency that is build be wise to district Government in the control torset. or civil servants and not engage. transparency that is build be wise to district Government in the control torset. or civil servants and not engage. transparency that is building to the Card Quality Commission transparency that is building to the Card Quality Commission transparency that is building to the Card Quality Commission control torset in a comparison to which they're entitled. the support they person of the society is a between the chard and protocol and apport needed in the discover frameworks of information, because you unless you have openness of information because you unless you have				
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8 co-chair of the National Haemophilia Database. She sits	7	is the current chair of the Organisation and the
9 towards the back of the room.	8	
	9	towards the back of the room.

9 towards the back of the room.
10 She is also, sir, as you may recall, the author of
11 the NHD statistics report that was provided pursuant to
12 the Inquiry's Rule 9 request.
13 At that opening hearing, my learned friend
14 Ms Richards noted that the Organisation had given the

15 Inquiry unrestricted access to all of its material, 16 physical and electronic, which she described as a huge 17 repository of material. Accessing that material has 18 involved or included the Inquiry's investigators 19 attending the National Haemophilia Database in 20 Manchester to inspect its paper archive. The volume of material is perhaps unsurprising given 21 22 that the Organisation spans the entire period of your 23 Inquiry, so it spans the period from the late 1960s 24 through to today. And as, sir, you know, the database

has collected statistics for the entirety of that

25

1	Haemophilia Centres across the UK today.
2	Since its inception, UKHCDO, as an organisation, has
3	attempted to support and advocate for people with
4	bleeding disorders, and this remains the main focus of
5	the Organisation today. So whatever factual
6	determination the Inquiry may reach as to the events of
7	these decades, the reasons for decisions made and taken,
8	and any culpability of individuals or organisations, it
9	should at all times be remembered that the infected and
10	affected were the innocent victims of events over which
11	they had no control.
12	Reading the written submissions of the
13	Core Participants on behalf of the infected and
14	affected, listening to the oral submissions of my
15	learned friend Mr Snowden and my learned friend
16	Ms Gollop over the last two days, watching the loving
17	and moving tribute to Lee shown on Tuesday only serves
18	to reinforce this point. The current executive of the
19	UKHCDO is acutely aware of the suffering of those
20	innocent victims, and, sir, it is determined to take to
21	heart the lessons to be learned from your report and to
22	implement fully any recommendations that you may make.
23	Sir, you designated the Organisation as a Core
24	Participant on 19 October 2018, following the acceptance
25	of an invitation which the Inquiry, I anticipate on your 86
	00

1	period.
2	As part of the Inquiry's disclosure exercise, we
3	have considered almost 6,000 documents at the request of
4	the Inquiry. That is 6,000 documents emanating from the
5	Organisation. We have taken no objection to disclosure
6	of any documents, and our comments to the Inquiry have
7	been confined to proposals for redactions.
8	As a consequence of that exercise, the Inquiry has
9	made available to Core Participants of the order of
10	2,800 documents which emanate from the UKHCDO. And
11	those documents have been available to Core Participants
12	on Relativity.
13	If you do the simple exercise of trawling through
14	who has disclosed what, you will see the UKHCDO's
15	disclosure is amongst the largest disclosure of all of
16	the Core Participants and, indeed, all of those who have
17	disclosed material to your Inquiry.
18	Can I, sir, reiterate, at the outset of my
19	observations, the UKHCDO's gratitude to the Inquiry. As
20	we explained in paragraph 7 of our submissions, our
21	written submissions, much of the focus of the
22	Organisation during the evidence hearing phase has been
23	on the preparation of the report to answer the Inquiry's
24	Rule 9 request for a UK-wide report on bleeding order
25	(sic) statistics.

1	I don't know whether, sir, you've seen the letter	1	organisations, and the reality is the Inquiry has been
2	making the request but effectively the letter said:	2	able to cut through red tape where we have not been able
3	Please could you provide an equivalent report to the	3	to. That has allowed us to complete the database, if
4	report that you provided to the Penrose Inquiry but for	4	I can put it like that, with up-to-date information,
5	the entirety of the UK.	5	particularly about cause of death.
6	For the sake of the transcript, and as I say, the	6	Sir, as we say in our written submissions, towards
7	author of which is Professor Chowdary, the report is to	7	the end at paragraph 276, our suggestion is that the
8	be found at WITN38226016.	8	report demonstrates the value of the database.
9	This was a very substantial piece of work. Again	9	I acknowledge that some have expressed concerns that
10	I say, unsurprising, given that the period that we	10	their data is held, whether by the database or at all,
10	looked at was one of more than 50 years, from 1969 to	10	but we would hope that, having now seen the report,
12	2020, that the Inquiry's request was that the data be	12	those who have been concerned can now see the merit or
12	set out on an annual basis, disaggregated, as the	12	at least some merit in that data being collected and
13	expression used in the letter, to centre, and specifying	13	being made available.
14	the amount of each product used.	14	Sir, we addressed issues of consent to the holding
16	Those who have read the report and, more	16	of data and access to data in our written submissions in
10	particularly, been through the spreadsheets, will	10	
18		18	paragraphs 53 to 64. I do not propose, unless you wish
10	appreciate the extent of the exercise. Sir, whilst much of the data and this is my	10	me to, to repeat those now, but I would direct anybody
19 20	-	19 20	to those paragraphs but, more particularly, to what is said on the UKHCDO website about addressing
	gratitude on behalf of the Organisation was already	20 21	information sorry, what is said on the UKHCDO website
21 22	computerised, some of it was not, and the Organisation	21	
	is grateful to the Inquiry for the assistance it's been	22	about addressing the information that is held and how to
23	able to provide to enable the final digitisation of the	23 24	go about accessing it. We believe that the database is without rival across
24	database, and perhaps more particularly for facilitating		
25	the exchange of information with NHS Digital and other 89	25	the world. Sir, we referenced in our written 90
1	submissions European research, including about the	1	The first sought clarification of information held
2	incidence of such databases, that showed in 2008 only	2	by the database concerning a relative of a witness who
3	a bare majority of European countries had a national	3	had given a statement to the Inquiry. It was a very
4	haemophilia patient registry, as it was referred to in	4	detailed enquiry in relation to "Why does it say [X]
5	that paper.	5	when I believe [Y]?"
6	By that stage, the database was entering early	6	I don't wish in any way to diminish the import of
7	middle age. We suggest that the value is underscored by	7	the request but it was confined, as I say, to a detailed
8	the work undertaken by your statistics expert group, and	8	enquiry about the entry for one patient on the database.
9	in particular, the complex modelling that it had to	9	The second request that we had related to criticisms
10	undertake to make an assessment of the impact of	10	made by Jason Evans, primarily about the legality of
11	infected blood on transfusion recipients, for whom there	11	data held on the database and information sharing, and
12	was no equivalent longitudinal data. In simple terms,	12	also the criticisms that are set out in the Tainted
13	sir, all one has to do is to compare the accuracy of	13	Blood document.
14	figures that the group provided for HCV and HIV	14	Those were the two Rule 9 requests that we received
15	infections, and also for deaths, for those with bleeding	15	in addition to that for the statistics report. Sir,
16	disorders, against those for people with blood	16	a number of clinicians have provided statements to the
17	transfusions, and you'll recall the breadth or the range	17	Inquiry about UKHCDO.
18	of possible accurate answers to the latter.	18	SIR BRIAN LANGSTAFF: I think the orchestra are leaving.
19	Sir, can I then just say one or two more words about	19	MR KENNEDY: I was going to recount a story about that but
20	the balance of our involvement with the Inquiry. Aside	20	I won't do it now, it's not the time or place.
21	from the Rule 9 request for the statistics report,	21	I was saying a number of clinicians had provided
22	UKHCDO received two further Rule 9 requests. They both	22	statements about UKHCDO or their involvement with the
23	emanated from criticisms that had been made by witnesses	23	Organisation, and some of those witnesses have given
24	who had either provided written statements or given oral	24	evidence to the Inquiry. Each has done so in a personal
25	evidence or a combination of the two.	25	capacity in this sense: their statements were prepared
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1	by their defence organisations or by, we anticipate,
2	their employing trusts. The UKHCDO legal team was not
3	involved in the preparation of the statements, and we
4	were told when we enquired about the Rule 9 requests
5	that they were confidential to the clinician.
6	Sir, the written evidence you have received in
7	relation to the UKHCDO has been prepared without any
8	input from the UKHCDO legal team. Now, that may well be
9	a good thing; it certainly would answer any suggestion
10	party line taken by the Organisation.
11	But it follows also from that that the witnesses who
12	have given evidence before you, none of those have been,
13	as my learned friend Ms Grey put it yesterday, supported
14	by, in this case, the UKHCDO legal team.
15	We explain in our written submissions that the
16	current executive of the Organisation has concluded that
17	it should not take a position on the issues that you
18	have to decide or the factual findings that you should
19	make. I am conscious that there was disquiet yesterday
20	when that stance was explored with my learned friend
21	Ms Grey, and I set out, if I may, the rationale for that
22	position.
23	There are three points. First, the UKHCDO is
24	a professional membership society. The Organisation is,
25	in effect, the sum of its individual members. It does
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1	as I put it, for the stance that we have taken of not
2	seeking to comment on what findings you should make or
3	indeed not make.
4	Sir, can I, acknowledging what I have just said,
5	just draw your attention to one or two matters, with the
6	greatest respect, about the fact-finding exercise, and
7	I do so conscious of what my learned friend Mr Snowden
8	said yesterday about the passage of time. I don't think
9	it can be said of the Organisation that we can't blame
10	something which is lay the blame for something which
11	is our fault, and I'm very conscious of the point that
12	he made to you, with which I agree, which is that you
13	are well familiar with dealing with issues of fading
14	memories, so I say no more about that.
15	But, sir, the passage of time or rather with the
16	passage of time come developments in practice and
17	changes in prevailing standards. The Inquiry may wish
18	to acknowledge and take that point into account.
19	I would then, if I may, respectfully adopt what the
20	Department of Health legal team said about guarding
21	against hindsight bias. I don't know if you recall it,
22	sir, or others recall it, we would underscore the maze
23	analogy, which they drew in their submissions at
24	paragraph 1.24.
25	They said this:
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1	not have a corporate identity or a corporate memory in
2	the same way that perhaps an NHS Trust might have.
3	Second, the current executive, and indeed membership,
4	self-evidently, is not made up of the same individuals
5	as the membership at the material time in the 1970s,
6	'80s and '90s and, much as the Inquiry has faced
7	challenges in obtaining accurate and reliable evidence
8	in relation to matters which occurred over 40 years ago,
9	the UKHCDO's membership and executive is not in
10	a position to comment definitively on events about which
11	they have little or no firsthand knowledge.
12	I underscore the point I made to you a moment ago,
13	sir, that those who have spoken about the UKHCDO have
14	done so with their, if I can put it likely this,
15	clinician hats on rather than their UKHCDO hats on.
16	Perhaps more importantly than either of those two
17	points is this: the current executive and the wider
18	membership of the Organisation have a continuing
19	therapeutic and professional relationship with some of
20	the infected and affected, and with others with
21	haemophilia. It is felt that for the Organisation to
22	take a position as to the merits of the issues with
23	which the Inquiry is concerned would be potentially to
24	compromise that continuing therapeutic relationship.
25	Sir, it is for those reasons that is the rationale, 94
1	"The first and fundamental point is that it is now

1	"The first and fundamental point is that it is now
2	potentially impossible to trace over the decisions of
3	the past"
4	They give the example in relation to the risk of
5	AIDS in the 1980s:
6	" without being influenced by the awareness of
7	what comes next. Rather like trying to retrace one's
8	way to the centre of a maze, which has been successful
9	negotiated, the route on the second journey into the
10	maze will be influenced consciously or subconsciously by
11	the previous successful trip or roadmap. Less weight or
12	attention given is to blind alleys or false starts that
13	seemed appropriate routes, even promising ones at the
14	time, but were later shown to be mistaken. Time
15	exploring them is more likely to be discounted. Equally
16	it may be harder to give credence or weight to the
17	intentions and plans of those involved at the time when
18	later shown to be flawed."
19	Again, sir, I acknowledge that is something you will
20	be familiar with overcoming, but I just, as I say,
21	endorse that point.
22	SIR BRIAN LANGSTAFF: Well, it used to be, early in my
23	career when I dealt with quite a lot of industrial
24	injury accidents in practice, I know some advocates
25	would say to a judge, "Well, look at the changes there

1	have been in practice now as a result of this accident.	
2	That should have been done beforehand", and it was never	
3	a proper answer.	3
4	MR KENNEDY: No.	2
5	SIR BRIAN LANGSTAFF: It might indicate, in some	Ę
6	circumstances, depending on the context, that more could	6
7	have been done, but it might not.	7
8	MR KENNEDY: It wasn't a complete answer.	8
9	SIR BRIAN LANGSTAFF: No.	ę
10	MR KENNEDY: No.	1
11	SIR BRIAN LANGSTAFF: So it's a question of context, and	1
12	context, I think, is knowing, as best one can, it is the	1
13	past and the past, as someone has said, is a foreign	1
14	country. But it's understanding, trying to understand,	1
15	as best one can, what the context was and bear in mind	1
16	what, at the time, the context should have been, if it	1
17	wasn't.	1
18	MR KENNEDY: Indeed. Indeed.	1
19	SIR BRIAN LANGSTAFF: It's a complex judgement.	1
20	MR KENNEDY: It is, indeed. We refer to it as context in	2
21	our submissions and indeed that is what it is.	2
22	Sir, I say this with a little trepidation, given	2
23	what Mr Snowden said on Tuesday, we undertook the	2
24	exercise of setting out a form of presentation I use	2
25	a small "p" rather than a large "P" from the 97	2
1	We simply, therefore, place the meeting in its	,
2	chronological context with other meetings of the	
3	Organisation, so as to permit you, sir, to take	3
4	a longitudinal view.	2
5	Sir, we set out the origins of the Organisation in	Ę
6	our written submissions. We explained that in the	6
7	absence of direct evidence we've drawn information from	7
8	material available on Relativity, some of which is from	8
9	our archive. I don't propose, you'll be glad to hear,	ç
10	to cover that ground orally. I will just say of the	1
11	Organisation: whilst we acknowledge that criticisms have	1
12	been and may in the future be made of the Organisation	1
13	and how it has acted in the past, and that it has been	1
14	slow to act in the past, there is countervailing	1
15	evidence that shows that the Organisation has at times	1
16	been a leader and not a follower.	1
17	I've mentioned in my submissions the database.	1
18	I would also mention its attitude towards the promotion	1
19	of comprehensive care. And again, sir, you may recall	1
20	that the 2008 European Inquiry stressed the importance	2
21	of comprehensive care.	2
22	I would add a third point, and it is this: it is the	2
23	introduction of professional peer review in Scotland and	2
24	Ireland in 1991, and England and Wales in 1992 and 1993,	2
25	and the Organisation believes that this is one of the	2
	99	

1	presentations that CTI have produced, of the minutes of
2	the meetings of UKHCDO and some of its working parties
3	to assist the Inquiry in this sense: by placing all that
4	material in chronological order and in one document,
5	with the guide to where it is to be found on Relativity.
6	We hope it is more than just a chronology. It was,
0 7	however, consciously a summary and nothing, sir, should
8	be taken from the amount of detail or the lack of detail
9	with which we have dealt with events in that part of our
10	written closing.
11	It is intended to be neutral. It includes material
12	that is both positive and negative, so far as the
13	
13	Organisation is concerned. So if it speaks, for
	instance, to the preference expressed by directors in
15	the early 1970s for imported concentrates. It speaks
16	equally to the views of the directors and the
17	Organisation that self-sufficiency had to be achieved
18	and had to be achieved soon, and we've endeavoured to
19	strike a balance as best we can.
20	My learned friend, Mr Snowden also said that we'd
21	said nothing about the Heathrow meeting in January 1983.
22	He is correct. I simply recorded that it had happened.
23	That was for the simple reason that we believe it was
24	an event that the Inquiry had considered in depth, and
25	the significance of which was largely obvious.
	98
1	earliest examples of professional peer review in the
2	NHS.
3	Sir, to give a chronological landmark, if I can put
4	it like that, the National Institute for Clinical
5	Excellence, what we know as NICE, now called the
6	National Institute for Health and Care Excellence, that
7	was set up in 1999. Now it's not a direct comparator
8	but maybe it will give you a chronological landmark. So
9	it's a little bit short of a decade behind the
10	introduction of peer review by the Organisation.
11	Sir, the Organisation aims to consider the
12	contemporaneous uncertainties in managing individuals
13	with bleeding disorders, to enhance the understanding of
14	inherited bleeding disorders and their management, and
14	6
	to improve the quality of care for this group of people.
16 17	As is typical of such professional societies, the
17	UKHCDO seeks to provide guidance where reliable evidence
18	is available. In the absence of good evidence it
19	provides a forum for examining existing information,
20	exchanging opinions and experience, and articulating
21	a consensus on the potential approaches to deal with
22	challenges reported in routine clinical practice. It
23	encourages collaboration, both nationally and
24	internationally.
25	A sure house instead out in surrounittees outbraissions
	As we have pointed out in our written submissions, 100

1	sir, these deliberations also permit the identification	
2	of unmet needs or service deficiencies.	
3	Since its inception, the membership of the	
4	Organisation has been drawn from all four home nations.	
5	This continues to be the case today, despite devolution.	
6	Hence the Organisation seeks to improve the quality of	
7	care of people with bleeding disorders, irrespective of	
8	the policies and priorities of their national	
9	commissioners and providers.	
10	That said, as we say in our written submission,	
11	healthcare policy is the province of the UK Department	
12	of Health, NHS commissioners and other designated bodies	
13	and their equivalents in the devolved nations.	
14	We seek to influence healthcare in clinical policies	
15	through interactions with members of these organisations	
16	and other national and regional bodies. But as we	
17	explain in our written submissions, we don't have a role	
18	in the accreditation or ongoing assessment of doctors.	
19	That falls to the General Medical Council and the Royal	
20	Colleges.	:
21	Sir, can I address one or two points arising from	:
22	the submissions of other Core Participants, and then	:
23	I have some comments to make about recommendations.	:
24	One recurring theme was that UKHCDO was dominated by	:
25	those at its head or by the largest Haemophilia Centres.	:
	101	
1	unincorporated organisation, and that remained the case,	
2	sir, as you will be aware, certainly up until the early	
3	'90s with charitable status and the limited company.	
4	So that was the status for much of the period you're	
5	concerned with. Whether, on the other hand, it was	
6	and I would add "inappropriately" so whether it was	
7	inappropriately dominated by the largest and most	
8	influential centres is a matter, sir, that you will have	
9	to wrestle with. I just make this observation: we've	
10	set out how the Organisation in its meetings changed	
11	over time in paragraph 66 and following of our written	
12	closing and you will have seen that, for much of the	
13	period, the Reference Centre Directors, as they were	
14	called, met at least biannually and all the directors	
15	once a year.	
16	It's perhaps unsurprising, if the directors of the	

1 Before looking at that briefly, can I just observe this: 2 from the outset, so that's back to Rosemary Biggs in 3 1968/9, and the early meetings of the 1970s, the 4 Department of Health, then the Ministry of Health, and 5 the blood transfusion centres, were regular attenders at 6 UKHCDO meetings, and the Department continued to be an 7 attender at meetings. And I've, I hope, captured that in that part of our written submissions. 8 9 Similarly, The Haemophilia Society was an early and 10 regular attender at the annual general meeting. The 11 first record that I can identify is 1 November 1974, the Relativity reference is HCDO0001017, but again we 12 13 capture that in our written closing. 14 My learned friend, on behalf of the Leigh Day Core 15 Participants, and I hope they'll forgive me if I give 16 them that name, described the Organisation as 17 a "voluntary and unincorporated association". That is SUBS0000059 210 at paragraph 26, where my learned 18 19 friends wrote this: 20 "It proved to be significant that this de facto 21 leadership organisation was a voluntary and 22 unincorporated association, essentially dominated by the 23 largest and most influential centres." 24 We certainly would agree with the first part of that 25 proposition, in other words a voluntary and 102

1	one personality or one or more personalities may
2	dominate. But whether the larger centres
3	inappropriately dominated, as I say, sir, is something
4	you may want to wrestle with. You may bear in mind that
5	their directors will have brought greater experience, if
6	not greater expertise, greater experience coming from
7	treatment of a greater number of patients.
8	My learned friends on behalf of the Thompsons Core
9	Participants make a similar point. They say the UKHCDO
10	was a club dominated by those at its head. In their
11	submissions, which is SUBS0000064_0247, at
12	paragraph 4.55, they said this:
13	"In the evidence heard by the Inquiry from
14	Government Ministers, the 'clinical freedom' [which they
15	put in inverted commas] which was championed as a means
16	of the Government evading ultimate responsibility when
17	things went wrong in the medical sphere. In fact, given
18	that the individual haemophilia clinicians were bound by
19	the diktats of this group, what is more, Dr Winter
20	described the group as being a form of club where the
21	views of the few at the top predominated. This approach
22	to centralised decision making by a few core individuals
23	had important ramifications for the care of haemophilia
24	patients generally, but also as for the formulation of
25	policy in the care of haemophiliacs in Scotland in 104

larger centres played a greater role for the simple

times a year, whereas the directors of Haemophilia

Centres or associate centres only once a year.

than a meeting of 78.

reason that they attended meetings three or perhaps four

That is for understandable reasons: a meeting of 10

or 12 is easier to organise, certainly in pre-Zoom days,

We know from personal experience that, in

organisations such as this, it is often the case that

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21 22

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1	particular."
2	I just say this: the observation of "dominated by
3	those at the top" we leave to you but we would just,
4	with respect, correct what my learned friends say when
5	they attribute that expression to Dr Winter.
6	Lawrence, if we can just bring up Dr Winter's
7	evidence. He gave evidence on 1 October 2020 and my
8	learned friend, Ms Richards asked Dr Winter the question
9	at the bottom of page 114 of the transcript. Thank you,
10	Lawrence.
11	She said:
12	"Can I ask you one further question about UKHCDO,
13	not at any one point in time, but in the knowledge that
14 15	you are about to become a member, in the end of 1983,
15 16	when you became a director in Kent.
16 17	"Professor Savidge, who you obviously dealt with
17	quite extensively over the following months and years,
19	in his evidence to the Archer Inquiry was very much critical of UKHCDO. He said it was run pretty much as
20	a club by the ten or so main players, and there was
20	something of an information vacuum for directors in
22	particular of smaller centres."
23	She asked him whether he would agree with that,
24	whether that was his experience once he became
25	a director.
	105
1	involved, of which Professor Savidge was a large one."
1 2	involved, of which Professor Savidge was a large one." Thank you, Lawrence.
2	Thank you, Lawrence.
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1	Forgive me, I paraphrase her final question. But
2	Dr Winter's answer is, we would suggest, informative.
2	He says:
4	"I don't agree with that. I think we should state
4 5	C C
-	UKHCDO was generally regarded by the other haemophilia
6 7	societies and doctors and other countries as actually
7	being a model of its kind. There isn't really any other
8	country where haemophilia doctors came together and
9	collaborated to such an extent that every patient with
10	an inherited blood disease in the country was
11	registered, we knew the number of patients with the
12	condition, we knew the severity of the condition, we
13	knew whether they had an inhibitor, we knew whether they
14	were on home treatment, we knew whether they were alive
15	or dead. No other [patient] had information like this.
16	And every time you went to a World Federation meeting,
17	people would say, you know, your system you have in the
18	UK is light years [I suspect he means 'ahead'] of what
19	we have in our country. We have nothing like it.
20	"Then, in addition to that, as we've seen already,
21	it was a very active organisation, in addition to all
22	the day-to-day work we were doing. At any one time,
23	there would be six, seven, eight working parties in
24	specialist areas. So I thought the UKHCDO was a very
25	good thing. Of course, there were personalities
	106
1	Dr Walford, that the guidance issued in June of 1983 was
2	weak because it was advisory rather than mandatory.
3	And, sir, perhaps I should just fill in the dots.
4	So the guidance that I'm referring to is that of
5	24 June 1983. I'm assuming that everybody is so
-	

invested in the detail of this case that they will know what I'm referring to, but it was the first guidance that came from UKHCDO that bore in mind the AIDS -- bore

9 in mind AIDS. 10 In terms of what the Organisation could and could 11 not achieve, we would agree with Leigh Day -- the Leigh 12 Day Core Participants -- when they say that we could not 13 have granted ourselves -- I paraphrase -- could not have 14 granted ourselves a power to make -- forgive me -- to 15 make binding clinical recommendations.

16 That is SUBS0000059_0212 at paragraph 33. 17 And we agree with what is self-evidently implicit in 18 that statement, which is that we didn't have that power. 19 Plainly, sir, it will be a matter for you whether 20 the guidance that was promulgated should have been 21 expressed in stronger terms. Both should have been 22 expressed in stronger terms, and should have been more 23 extensive or more expansive. But we would simply say to 24 you, sir, that the Organisation was not in a position to 25 mandate or direct practice, the practice or treatment 108

1	provided by clinicians.	1
2	There are perhaps two relevant points to make.	2
3	First, we had no power to do so. But we also had no	3
4	means of enforcing a direction. And if you, sir	4
5	I can see you perhaps mentally posing yourself	5
6	a question. If you look, for instance, at the guidance	6
7	issued in 1997 in relation to recombinant products, and	7
8	I touch on that in my written closing, even that it	8
9	may be said it goes further than what was said in 1983,	9
10	but even that doesn't say, "You must do this". It says,	10
11	"You should".	11
12	So it seems to us that the question is whether the	12
13	guidance should have been expressed more strongly rather	13
14	than it should have been set out in mandatory terms.	14
15	We would also just invite you to bear in mind that	15
16	if this guidance was to be expressed in mandatory terms,	16
17	it would have had to apply not just to Haemophilia	17
18	Centres but to any hospital that might treat	18
19	a haemophiliac and, indeed, arguably across the board,	19
20	because it would be relevant to those receiving blood	20
21	transfusions. So we would respectfully suggest that, if	21
22	mandatory guidance was required, it needed to come from	22
23	a body with greater and broader authority than UKHCDO.	23
24	I think acknowledging that point, the Leigh Day Core	24
25	Participants suggest that the Organisation should have	25
	109	
1	time of the variant CJD concerns.	1
2	Can I deal then with one matter which arises in the	2
3	submissions made by the Collins' Core Participants.	3
4	It's a short point, and it's just this: when discussing	4
5	the issue of candour, albeit in the context of a chapter	5
6	on ministers, but in a chapter that is a proposition	6
7	that is repeated in the chapter on clinicians, my	7
8	learned friends say of the article that Dr Peter Jones	8
9	wrote to the Press Council and sir, if it helps,	9
10	I can ask Lawrence to bring that up.	10
11	So this is PJON sir, this is the, forgive me,	11
12	article letter. So this is the letter that	12
13	Dr Peter Jones wrote on 6 May 1983, complaining about an	13
14	article that had been in The Mail on Sunday five days	14
15	before.	15
16	My learned friends say that Dr Jones was writing on	16
17	behalf of UKHCDO. And it's that latter part which	17
18	concerns me. There is, of course, a legitimate question	18
19	for you to address as to whether Dr Jones was right	19
20	to sorry, was correct to write in the terms that he	20
21	did. And it may be I accept maybe that others within	21
22	the Organisation shared the sentiments that he expressed	22
23	in this letter. But we're unclear whether it is correct	23
24	to say that this was the Organisation seeking, as my	24
25	learned friends put it, to shut the story down.	25
	111	

	itself to be put on a statutory footing. We're not
	clear how that could have been achieved but it seems to
	us that that would have had two main drawbacks. First,
	the Organisation would have become simply another arm of
	Government or the Department, and it's unclear to us
	where the Organisation would have sat, for instance, in
	relation to a body such as the CSM.
	There is also evidence that you have seen, sir, and
)	heard, that at times the Government didn't listen to the
I	Organisation anyway. Perhaps more significantly from
2	the Organisation's perspective, had that happened, it
3	would have lost its independence and it would have
1	significantly curtailed, we would suggest, its ability
5	to speak on behalf of those with bleeding disorders and
6	indeed those treating them.
7	I'm conscious of time. I'm moving slower than I'd
3	anticipated, but there are three examples and I will
9	take them very briefly: one is self-sufficiency; two is,
)	as I mentioned earlier, recombinant products, where the
l	Department's response was "We're not going to sign off
2	your guidance because" well, I'll leave others to
3	answer the "because"; and the third example is what
1	happened in relation to variant CJD, and what the
5	Organisation said about the use of domestic blood at the 110
	I deal with, if I may jumping on to something

sought to put -- forgive me -- should have asked for

1	I deal with, if I may jumping on to something
2	that my learned friends for the Milners'
3	Core Participants say. The reference to their
4	submissions is SUBS000005_0117, at paragraph 350. It's
5	just a correction of a Relativity reference but they say
6	this, they say:
7	"Nevertheless by January 1983 the issue of AIDS
3	remained a footnote or afterthought in the minute of the
9	meeting of the UKHCDO which took place on 8 January that
0	year. The directors noted that AIDS was similar in its
1	epidemiology to HPV and that the working party ought to
2	enquire about the likely transmission of the disease
3	through blood and blood products.
4	"In our submission, this lack of recognition of the
5	severity of the risk posed is characteristic of the
6	UKHCDO's lethargic approach to addressing emergency
7	threats."
8	Sir, the short point is this: that "footnote or
9	afterthought", as they put it, was not 8 January 1983.
0	It was a meeting that the Relativity reference is
1	this: HCDO000003_058. That is a Relativity reference
2	to a meeting sorry, the minutes of a meeting of
3	the sorry, of the Hepatitis Working Party on
4	13 September 1982. And the date may be important for
5	the allegation of lethargy, but you will appreciate that 112

1	comes about the midpoint between the two CDC letters	1	significant changes. Today's patient is much more
2	of 1982. A meeting of the Hepatitis Working Party took	2	prepared to question his or her doctor than the patient
3	place on 19 January 1983, and it's apparent from the	3	in the 1960s, '70s or '80s.
4	meetings sorry, apparent from the minutes that AIDS	4	Moreover, we would suggest that in reality, with the
5	was one of the central issues that was addressed.	5	increasing use of evidence-based medicine, the
6	Sir, that we address in our submissions at	6	acknowledgement that departure from guidance needs to be
7	paragraph 124.	7	justified and informed consent sought, the advent of
8	Sir, two further matters which arise from	8	organisations such as NICE means that clinical
9	submissions. One is this: it relates to the issue of	9	freedom or rather there is less clinical freedom now
10	clinical freedom. A number of the Core Participants	10	than there was 30 years ago. Moreover, we would caution
11	have warned or cautioned of the perils of unfettered	11	reaching conclusions about clinical freedom based upon
12	clinical freedom, and some have hinted to a suggestion	12	what I might refer to as a small sample size, so having
13	that there is need for a review and qualification of	13	looked at one discrete area of medicine, and equally,
14	clinical freedom.	14	caution recognising, as one of your expert groups
15	Can we just say this in response to that. As we	15	recognised, that clinical freedom permits incremental
16	said a moment ago, sir, the practice of medicine has	16	change in practice.
17	changed substantially over the years with which you are	17	Then, sir, if I can just turn briefly to research.
18	concerned. There have been extraordinary advances in	18	Again, much has been written and said about research.
19	treatment, both surgical and medical.	19	The Organisation would accept that, during the relevant
20	There has, we would suggest, also been a change in	20	period, clinicians who were UKHCDO members conducted
21	what we might term the "deference" that a patient has	21	studies in the sense of clinical trials or what might be
22	for his or her doctor. There are, legitimate no doubt,	22	referred to as interventional research. We would also
23	criticisms of a paternalistic attitude in the 1970s, and	23	accept that these studies were often discussed at
24	indeed later. We don't say that that has been abolished	24	meetings of the Organisation, and we have referred in
25	in its entirety, but I think we can all recognise	25	our written submission to discussion of, for instance,
	113		114
			114
			114
1	trial protocols.	1	undertaken by Dr Rizza, during later periods.
1 2	trial protocols. I just wish to make this clear on behalf of the	1 2	
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1	Mr Snowden took on Tuesday of identifying matters which	1	the uni
2	perhaps the lawyers weren't concerned about but the	2	It had I
3	clients were and he identified natural clearers as	3	could b
4	being falling into that category, and I identify that	4	compre
5	too. Now, that was something that was specifically	5	that ha
6	mentioned to me when we were providing our setting	6	At
7	out our response to recommendations. And so what we	7	compre
8	would say or rather what the Organisation would say is	8	a centi
9	particularly encapsulated in what Ms Francis and I wrote	9	doctor
10	at paragraph 262. I say no more than that.	10	peer re
11	Haemophilia Centres I think my learned friend	11	identifi
12	Ms Gollop adopted that earlier, but it's if I	12	comple
13	l can take it in more detail if you wish	13	١c
14	SIR BRIAN LANGSTAFF: No, I've read it more than once.	14	the, I t
15	MR KENNEDY: Then I wouldn't make you read it again.	15	Buggir
16	Then just if I may, Haemophilia Centres are centres	16	l don't
17	of excellence. We support the suggestions made by other	17	wholeh
18	Core Participants that Haemophilia Centres should be	18	Tł
19	centres of excellence. It will come as no surprise, as	19	highlig
20	we say in our written submissions, that the central	20	commi
21	issue is one of funding. Both, as we put it, adequacy	21	the UK
22	generally, and consistency and transparency.	22	for all o
23	We note at paragraph 265 that collaboration between	23	bleedir
24	UKHCDO and the Haemophilia Society and the Commercial	24	compre
25	Medicines Unit resulted in a very significant saving in 117	25	service
1	of all stakeholders, with particular focus on those with	1	if I can
2	bleeding disorders so that their views are not just	2	not ha
3	heard but actively addressed.	3	when i
4	Sir, we set out at 267 a form of words which may or	4	that's \
5	may not find favour.	5	about
6	Then, if I may, just turning to what I've described	6	variant
7	as the future of UKHCDO and the National Haemophilia	7	
8	Database. Just referencing what I said a moment ago about	8 9	MR KENNE Profes
9 10	service standards, we would anticipate that the UKHCDO	9 10	1997, v
11	will, as it has done in the past, and in conjunction	10	to collo
12	with other patient organisations, play a significant	12	wary o
13	role in any future discussion about service	12	CJD.
14	specification.	13	W
15	We suggest that its ability to play that significant	15	that ha
16	role reflects its position, or the position that it	15	indepe
17	occupies, standing between the patient and the	10	arguat
18	Department, and it permits the Organisation to advocate	18	society
19	for patients to commissioners and to the Department, and	10	retrogr
20	it's for that reason that we would resist any suggestion	20	gratefu
21	that the organisation go into a form of public	20	from th
22	ownership.	22	At
23	I said earlier that I mentioned three points about	23	this:
24	independence. I'll just say briefly this: had, by way	24	uno. "T
25	of illustration, UKHCDO been within the Department tent,	25	curren
-	119		

1	the unit cost of medicines due to UK-wide procurement.
2	It had been hoped that some of the savings generated
3	could be used to support the development of
4	comprehensive care. Sadly, that was not the case
5	that has not proved the case.
6	At 264, we point out that the provision of
7	comprehensive care is the first step to becoming
8	a centre of excellence, and this requires a team of
9	doctors, nurses and allied professionals. Unhappily,
10	peer review undertaken by the Organisation has
11	identified persistent problems securing a full
12	complement of multi-disciplinary team members.
13	I can just add at this point, we've seen what one of
14	the, I think unrepresented, Core Participants Elisabeth
15	Buggins says about multi-disciplinary teamwork
16	I don't know if she's here today, but we agree
17	wholeheartedly with what she says.
18	The problems, and some of the solutions, we are
19	highlighting in paragraph 266. In summary,
20	commissioning must be cohesive and standardised across
21	the UK. There must be a single service specification
22	for all of the UK to ensure that all people with
23	bleeding disorders have access to high quality and
24	comprehensive care. And thirdly, any update of the
25	service specification must be taken with the involvement
	118
1	if I can put it like that, in 1996 and 1997, it would
2	not have been able to speak in the terms in which it did
3	when issuing guidance about recombinant products
4	that's WITN3289048 nor in the terms in which it did
5	about plasma collection from UK donors at the time of
6	variant CJD that's WITN7034006.
7	SIR BRIAN LANGSTAFF: Just give me that number again.
8	MR KENNEDY: Sorry, forgive me, WITN7034006. That is
٥	Professor Ludlam's letter to The Lancet of December

2	not have been able to speak in the terms in which it did
3	when issuing guidance about recombinant products
4	that's WITN3289048 nor in the terms in which it did
5	about plasma collection from UK donors at the time of
6	variant CJD that's WITN7034006.
7	SIR BRIAN LANGSTAFF: Just give me that number again.
8	MR KENNEDY: Sorry, forgive me, WITN7034006. That is
9	Professor Ludlam's letter to The Lancet of December
10	1997, where he made two points: (1) what one might refer
11	to colloquially as Recombinant for All; and (2) to be
12	wary of UK donors, given what was known about variant
13	CJD.
14	We would therefore suggest that a recommendation
15	that had the impact of reducing or removing the
16	independence of an organisation such as UKHCDO, and
17	arguably would be carried over to any professional
18	society that one might name, would be a significant
19	retrograde step. We note in this respect, sir, and are
20	grateful for, the support that the Organisation receives
21	from the Scottish territorial health boards.
22	At paragraph 220 of their submissions, they say
23	this:
24	"The UKHCDO and the British Society for Haematology
	ourrently provide guideness on entired treatment for

currently provide guidance on optimal treatment for 120

1	people with bleeding disorders. Those organisations and	1	said towards the conclusion
2	the National Haemophilia Database also raise awareness	2	statistics group and we woul
3	of developments in patient safety concerns. This work	3	about funding and about the
4	is of great value in terms of both keeping clinicians up	4	epidemiological input.
5	to date on best practice and enabling rapid	5	I just say this of the data
6	identification of new safety concerns."	6	we think it's a that the fir
7	They give a recommendation about security of	7	database to be established i
8	funding.	8	that has been adopted elsev
9	On the issue of the future of the database, just	9	foresight of clinicians such a
10	briefly this, sir: we believe that it is uncontroversial	10	at all. It is a tribute to those
11	that a database should be maintained to track disease	11	who encouraged and cajoled
12	incidence, prevalence, trends and clinical outcomes and,	12	recalcitrant centres to submi
13	in particular, mortality over time.	13	their work, the database mig
14	As I said earlier, that permits identification of	14	to exist, as, sir, you know ha
15	unmet needs in the context of an evolving therapeutic	15	I acknowledge that thos
16	and organisational landscape, and it informs healthcare	16	to are people who may elsev
17	planning. It is also consistent with the	17	Our simple concern, or
18	recommendations for the European Association of	18	simple concern, is that a pro
19	Haemophilia, as I mention in my written closing.	19	a proposal of incorporating t
20	I've addressed you already on what we say is	20	wider NHS would expose it t
21	demonstrably the value of the database of the exercise	21	that we hear and read about
22	that the statistics group had to undertake. We don't	22	it vulnerable to compromise
23	detect within the statistics group, report or the oral	23	spending priorities. And we
24	evidence, a particular concern about shortcomings of	24	must be significant doubt that
25	data selection but we do recognise what Professor Bird	25	under NHS management for
	121		
1	of the period with which you are enquiring, then you may	1	Sir, can I just conclude
2	well not have had access to the same extent of	2	UKHCDO. I say this to Lee's
3	longitudinal data that you have received.	3	spoke on Tuesday, who is d
4	That said, we acknowledge that the database must	4	positive should come from h
5	adapt and change to meet future needs. There must be	5	Barbara, who spoke most m
6	continued involvement of those with bleeding disorders	6	will speak after me from this
7	on the management group. And again, we've touched on	7	and to the many, many more
8	that in writing.	8	evidence before you, sir, wh
9	I just add one final point, which is perhaps	9	We, on behalf of UKHC
10	relevant to ownership. Under the stewardship of UKHCDO,	10	report provides you with the
11	the database provides UKHCDO with access to the	11	campaigned for and that you
12	information from which it can generate treatment	12	Sir, thank you. That is a
13	guidance. If they were divorced one from the other,	13	of UKHCDO.
14	it's unclear to us how the data would be accessed or		SIR BRIAN LANGSTAFF: Thank
15	whether the Organisation would end up paying the	15	Inquiry recognises and than
16	database for the data.	16	has supplied to our statistica
17	My last matter in terms of peer review is just this,	17	Inquiry to produce the degre
18	sir: you well have seen that WMQRS, West Midlands	18	that is available.
19	Quality Research (sic) Service I think, ceased to exist	19	Thank you very much.
20	during the Covid pandemic. And the Organisation is		MR KENNEDY: Thank you, sir.
21	seeking to put in place arrangements for peer review or		MS RICHARDS: Sir, tomorrow, t
22	audit for the forthcoming round. I am sure that the	22	10.00 Ms Monaghan, on beh
23	Organisation will keep you updated if you wish as to its	23	represented by Saunders So
24	progress, but we cannot say anything more at this stage	24	have Ms Maharaj, who is the
25	than we have said in writing	25	Thalassaamia Society

than we have said in writing.

25

on of the evidence of the uld endorse what she says ne need for greater atabase: I said earlier that first comprehensive in the world. It's a model ewhere. It is a tribute to the as Dr Biggs that it exists e in the 1970s and 1980s ed sometimes reluctant or nit their data. Without ight have withered and ceased appened in Canada. ose people I have just referred ewhere be criticised. r rather the Organisation's roposal -- accepting the database within the to the budgetary constraints ut every day. It would render e due to decisions about e would suggest that there hat had the database been or the entire period or for much 122

1	Sir, can I just conclude with this on behalf of
2	UKHCDO. I say this to Lee's family, to Andrew, who
3	spoke on Tuesday, who is determined that something
4	positive should come from his experience, I say it to
5	Barbara, who spoke most movingly yesterday, to those who
6	will speak after me from this lectern in the coming days
7	and to the many, many more people who have given
8	evidence before you, sir, whether on paper or in person.
9	We, on behalf of UKHCDO, hope that Sir Brian's
10	report provides you with the answers that you have
11	campaigned for and that you deserve.
12	Sir, thank you. That is all I have to say on behalf
13	of UKHCDO.
14	SIR BRIAN LANGSTAFF: Thank you very much, Mr Kennedy. The
15	Inquiry recognises and thanks the UKHCDO for the data it
16	has supplied to our statistical experts enabling the
17	Inquiry to produce the degree of statistical certainty
18	that is available.
19	Thank you very much.
20	MR KENNEDY: Thank you, sir.
21	MS RICHARDS: Sir, tomorrow, then, we have in the morning at
22	10.00 Ms Monaghan, on behalf of the Core Participants
23	represented by Saunders Solicitors, and then at 2.00 we
24	have Ms Maharaj, who is the vice chair of the UK
25	Thalassaemia Society.

1	SIR BRIAN LANGSTAFF: 10.00 tomorrow.	INDEX	
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