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 Eli sabeth and Jonathan Buggins, and	12	done about the results. That was the attitude."
13	some of you may remember listening to Eli sabeth, 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, who is the widow of John Prothero, a member of	15	I just mentioned.
16	the Executive Committee in the 1980s; Andrew Martin,	16	Her son Jonathan has made a statement to the
17	Paul Sartain, and David Watters, whose evidence many of	17	Inquiry , not yet disclosed. His elder brother was
18	you will also remember, he was the general secretary of	18	Richard, the one who died in 1986 , and Jonathan's
19	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	20	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 disturb ed 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 last ly, 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."
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It all sounds horribly familiar. First Do No Harm

is a document which I will come back to . if I have time .

The Society asks the Inquiry to find that it and its 1 which caused almost 100 deaths. Mr Snowden quoted that 2 members were fortunate to have the services of part of the report where the Bishop explained how he 3 Mr Watters. Prior to joining the Society he was came by the phrase "the patronising disposition of a social worker and he worked particularly with homeless 4 unaccountable power" and talked about the experience of people. And after leaving the Society, which he did not 5 the Hillsborough families when , in all innocence and want to do, he worked for another healthcare 6 with a good conscience, they asked questions of those in charity. His motivation throughout his professional 7 authority on behalf of those they loved, and found the life was to improve the lives of others less fortunate institutions closing ranks . than himself, and he worked tirelessly in pursuit of 9 He went on to say this: that goal. He advocated for people with haemophilia at 10 "And so the Hillsborough families' struggle to gain benefit tribunals. He campaigned for financial relief 11 justice for the 96 has a vicarious quality to it so that for those infected with HIV. He was there at the start 12 whatever they can achieve in calling to account those in of the campaigns for hepatitis C compensation. And he 13 authority is of value to the whole nation. " was a gifted administrator. He and the Reverend Tanner 14 "The concerns that it deals with are both historic were patently good men doing the best they could for the 15 and contemporary." 16 entire bleeding disorder community in close to That applies just as much to all of you. Everything impossible circumstances. And you will all know that 17 that you've done has had the same vicarious quality to 18 the Reverend Tanner's son Mark died of infected blood it, and everything that you have done will be of benefit related illnesses and was ill throughout much of the 19 to the nation. The concerns of this Inquiry go further time that the Reverend Tanner was chair of the Society. 20 back even than the events of Hillsborough, and as 21 Those are the pen portraits. I now want to quote yesterday's submissions on behalf of the DHS C, to which from two reports. The first quotation is the same one 22 I'll return in a moment, amply demonstrate, they are not 23 that Mr Snowden gave you on Tuesday from the only contemporary, but pressing. Bishop Jones' November 2017 report on Hillsborough. 24 The second quotation is from Baroness Cumberlege's That was the crush at a football stadium in April 1989 25 report First Do No Harm, and that was published midway 6 through this Inquiry in July 2020. Some of the matters 1 so I'd like to put it on screen so that those of you who into which her review inquired dated back to 1950, very 2 are understandably not familiar with it can see the similar to this Inquiry. The passage of time and the 3 similarities here . fact that attitudes, cultures, communication, and so on, 4 Thank you, Lawrence. You're ahead of me, which is have changed over the decades did not prevent the 5 great. Page -- we've got paragraphs 1 .1 to 1.3 and Baroness from getting to the heart of the matter and 6 those are on internal page 0009. That looks like 18. they won't stand in your way, sir, either. Much of the evidence of this Inquiry corroborates 8 It's really close type. I don't know if we can her conclusion, and this is what she said: 9 enlarge 1.2. Very briefly, so that it makes sense, this "We have found that the healthcare system in which 10 is what she was looking at : hormone pregnancy tests , I include the NHS, private providers, the regulators, 11 which were taken off the market in the late 1970s. and professional bodies, pharmaceutical and device 12 thought to be associated with birth defects and manufacturers and pol icy makers, is disjointed, siloed, 13 miscarriages; sodium valproate, which is unresponsive and defensive. It doesn't adequately 14 an anti-epileptic, which causes physical malformations. recognise that patients are its raison d'etre . It's 15 autism and development delay in children when taken by failed to listen to their concerns and when belatedly 16 their mothers in pregnancy ; and pelvic mesh implants it's decided to act it has too often moved glacially. 17 used in the surgical repair of organ prolapse and to Indeed, over these two years we have found ourselves in 18 manage urinary incontinence , linked to crippling, the position of recommending, encouraging and urging the 19 life-changing complications. 20 system to take action that should have been taken long If we look at page 0011, she identified right at the ago. The system is not good enough at spotting trends 21 bottom 16 common and compelling themes which chime very 22 much with your experiences. Number 1: in practice and outcomes that give rise to safety 23 concerns. Listening to patients is pivotal to that. "the lack of information to make informed

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choices ..."

Then over the page .

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(2) Pages 5 - 8

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 ;	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 mother s' 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 father s', husbands', brother s':	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
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 to o 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	Sir Brian, your attention to detail and your very	10	from the Prime Minister down.
11	personal involvement have been notable features every	11	When we were informed at the end of the day on
12	single day of this long -running Inquiry. If the culture	12	Tuesday that the Department's submissions would not
13	that your vision for your Inquiry has created could be	13	start at 10.00 as timetabled but instead at 2.00, and be
14	exported into the NHS and Government more widely, that	14	over by 3.00, there were a lot of questions about what
15	would be grounds for hope for a state that is more	15	that might mean. There was, within the Society,
16	listening, compassionate and responsive to the needs of	16	a degree of expectation that the submissions were going
17	those it here to serve.	17	to be short because the Government had something of
18	Which brings me to yesterday. We're all familiar	18	substance to announce. Instead, time that could have
19	with the phrase "actions speak louder than words".	19	been put to good use by infected and affected Core
20	Yesterday we got no actions and no words. But , more	20	Participants was wasted.
21	precisely, we got a lot of words that said nothing at	21	In September 2018 Ms Grey informed the Inquiry that
22	all. The first thing to say is that none of that is the	22	the Department accepted that things happened that should
23	fault of Ms Grey, King's Counsel, or her team. I have	23	not have happened and that it was sorry. Yesterday , she
24	no reason to doubt, and I think you should not either,	24	delivered the astonishing news that after a four-year
25	that she and her team have worked hard and to a very 11	25	opportunity to reflect on those things that should not 12
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(3) Pages 9 - 12

1 1 nothing and they deserve something now. There is have happened, the Department had somehow gone backwards 2 2 and is now unable to identify what it was sorry for when reason to believe that the Government will do anything 3 3 the Inquiry started. There's been some sort of without a recommendation from you. 4 groupthink amnesia. 4 Third, it is absolutely imperative now that this Inquiry does not end with the publication of the report. 5 Ms Grey referred to the fact that on 15 December, 5 6 the Cabinet Secretary told the House of Commons that the For as long as your Inquiry is alive, Sir Brian, people 7 Government accepted moral responsibility for infected have trust and hope that there will be accountability, 8 blood but, yesterday, it was unable to say through its compensation and lasting change. The fear is that , as 9 lawyers why it has accepted moral responsibility or what 9 soon as you close this Inquiry , there may be delay, 10 that actually means. 10 backsliding and nothing will really change. We would 11 My clients accept that they cannot force the 11 not want see your report to be as widely disregarded as 12 Department to say what it is sorry for. Sir Brian had 12 it would appear Bishop Jones' report into Hillsborough 13 a go, and if he can't make that happen then neither can 13 has been. 14 we. But the cowardly approach taken by the Department 14 Yesterday rather proved that that fear may well be 15 has three consequences: first, what little trust there 15 well founded. A way must be found to hold the 16 16 Government's feet to the fire after the report is might have been has gone 17 Second, and this was not the Society's position 17 18 18 before yesterday afternoon, it now joins with the Ms Grey mentioned Mr Quin's statement in the House 19 submissions of Mr Snowden, King's Counsel, on behalf of 19 of Commons on 15 December. We would mention the debate 20 those represented by Collins, that there need to be 20 in the House of Lords on 20 December last year, five 21 21 days later. I've given the reference to Ms Richards, further interim recommendations on compensation for 22 parents, children and grandchildren who have been 22 and we'll make that reference available to you, 23 23 bereaved by infected blood. The payments of £100,000 Sir Brian. 24 were only paid because , Sir Brian , you made an interim 24 There is a transcript of the debate on the 25 recommendation in that regard. Bereaved people have had 25 TheyWorkForYou.com website , which you may be interested 13 1 to read. Baroness Neville-Rolfe, who is the Minister 1 the need for the working group to listen to infected and 2 for the Government in the House of Lords, said that 2 affected people's views on the compensation framework 3 Ms Sue Gray, at the Cabinet Office, is bringing together 3 they want and need now, not when the finished product is 4 permanent secretaries from the Treasury, HMRC, the 4 delivered 5 Cabinet Office, DHSC, the DWP, the DLUH C, (I think 5 Returning briefly to the Government's implementation 6 that's the levelling up one), the Devolved Nations and 6 of the Cumberlege Review's recommendations, the Society 7 others. She told the House of Lords that this group met 7 notes -- and it's one of my New Year 's resolutions to 8 monthly and that -- this is a quote: 8 stop bombarding Ms Richards with emails telling her to 9 "It is gearing up , thinking about the IT systems and 9 listen to Woman's Hour -- that she gave an interview to 10 how we ensure that we contact people who might want to 10 the BBC -- there was an interview on Woman's Hour on 11 seek compensation , once we know the precise framework 11 3 January 2023 , given by the Patient Safety 12 12 Commissioner. That was a recommendation of Baroness and make sure that everyone can respond. Publicity is Cumberledge 's report and Dr Henrietta Hughes has been in 13 very important with these public issues and noble Lords 13 14 across the house can help with that so that people know 14 post for some months now. 15 what is happening." 15 Dr Hughes talked about the mesh removal centres 16 She then said that careful consideration was being 16 which have been set up in response to the Cumberlege 17 given as to whether there should be an arm's length 17 Review's findings and Dr Hughes told the BBC that these 18 body. She said the Government would want to work with 18 centres are not meeting the needs of users because when

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"people affected" and acknowledged the work of the APPG.

She said she'd make progress statements to the

house. On 11 January this year, in a written answer to

cross-Government working party was taking forward work

The Society makes three points. The first is about

a Parliamentary question, Mr Quin said that the

on the establishment of an arm's length body .

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the clinics and systems were designed, the views of the

is concerned that the same error may be being repeated

right now in relation to the working group setting up

the infected blood compensation framework

and. Sir Brian, we might like to tempt you into

women harmed by mesh were not listened to. The Society

Second, transparency. The Society would suggest

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considering an interim recommendation -- that it is reasonable to ask that we have published (i) and members of the working group; (ii) the dates of their meetings and the agenda and minutes ; and (iii) that there are regular publicly available written progress reports . Infected and affected people shouldn't have to scour the Internet looking for reports of debates in the House of Lords to find out what is going on. If the working group wanted to report, they could do so to this Inquiry and keep this Inquiry in the loop, not just make statements in the House of Lords. Third, just going back to that quote about what the working group is currently doing, thinking about the IT systems and how we ensure that we contact people, it's hard to know where to start. Shout out to Baroness Neville-Rolfe and her colleagues : come on down to Aldwych House. People here are very nice. They don't b ite and you can talk to them and you can listen to them and you can find out what

they need, and there are a whole load of people sitting

to contact right here and right now. You really don't

publicity work for you . It's all here, handed on

a plate, if you would only like to come and listen.

need to ask members of the House of Lords to do your

behind me who could probably give you the list of people

Before I look at those , a word about money and the cost of haemophilia. I'm going to quote from a document that's on the website which is a collection of pieces from the British Medical Journal , and I give a trigger warning that it contains language and an ethical stance which may be offensive. It goes without saying that the Society wants to make it very clear that it's not its position that anyone in Government or the NHS intended the death of any patient or section of the public but that this is an important part of the context of the lives of people with haemophilia at the beginning of the 1970s.

The Society was always mindful that if NHS money was going to be spent on haemophilia treatment, the Government would want to see that justified financially, but there was actually more at stake. In 1971, the BMJ published a profile opinion piece that had coverage in the national press, arguing that the successful treatment of haemophilia, especially for severe cases, was enabling not only the survival of these high-demand patients but also their likelihood of having children. This is the quote:

"If we continue the policy of treating such sufferers with the full resources of modern medicine, we shall spend a steadily increasing proportion of the There's still time.

You've had a long time to think about what you want and what you need from a compensation framework. You should be in the tent, not outside it.

I'm going to turn now to the past. These submissions look at the past, the present and the future. They're focused on the future because that's where the Society can make a positive difference for people who are suffering now and for future generations of people with a bleeding disorder. In not touching on the past at greater length, the Society isn't seeking to evade scrutiny, and we have tried to explain its knowledge of risk and its actions particularly in the 1980s, as thoroughly as possible in written submissions.

We've asked the questions : why did the Society support the importation into the UK of US blood product that it knew carried a higher hepatitis risk than UK treatment, before the UK had achieve d self-sufficiency?

From '83 to '85 , why did it tell its members that the risk of being treated with US products and getting AIDS was outweighed by the risk of not being treated at all and why did it press the Government to continue importing US products that it knew could be contaminated with AIDS even when it was known that AIDS was a killer disease for which there was no cure?

national income for their benefit and reduce the proportion available for the care of other forms of illness, education, technical development , and so on.

Are we prepar ed to pay such a price and increase the number of biochemical cripples fourfold in a generation Is not this too high a price to pay for our comfortable glow of companionable humanity? "

Later correspondence in the BMJ was consistently critical of that stance and there was never any further discussion of eugenics with regard to haemophilia.

But the cost of keeping people with haemophilia alive has never gone away. One thinks, for example, of the Society's campaign for Recombinant for All in the late 1990s and the fight to get that extended from children to adults and the restricted access on cost ground to Harvoni, for example, that was still taking place as late as 2016, the year before this Inquiry was announced.

When preparing for the Archer Inquiry, one of the documents that the Department of Health was concerned might cause some embarrassment was a March 19 85 document, and that was a memo that said:

"Steps to prevent the remainder of the haemophiliac population becoming seropositive are likely to have a strong cost benefit plus in terms of lives saved. Of

(5) Pages 17 - 20

course, the maintenance of the life of a haemophiliac is itself expensive and I'm very much afraid that those who are already doomed will generate savings which more than cover the cost of testing blood donations."

A few points may be made. First, and most obviously, the fact that lives of people with haemophilia is expensive is not the fault of

obviously, the fact that lives of people with haemophilia is expensive is not the fault of haemophiliacs. People with rare diseases exist in every population and in countries with a developed healthcare system, part of the duty of government is to protect them as much as everybody else. Second, freeze dried large pool concentrates were welcomed partly because they were seen as an improved means of enabling the bleeding disorder community to make a financial contribution .

In 1979, the Department of Health and Social Services sponsored a study into home treatment and found that it "provided savings in time lost from school and work, a greater sense of security, and increased capacity for planning ahead".

In 1989 the Reverend Tanner wrote to Norman Lamont seeking more financial support for people with haemophilia infected with AIDS and explained that "they became infected through their use of prescribed medication in an earnest desire to maintain their health

commissioning a study to look at the financial contribution people with haemophilia could make by using home treatment, working, and contributing to the economy. And six years later, in 1985, the Department was taking into account the contribution they would make to the cost of testing for AIDS by dying of AIDS.

People with haemophilia were vulnerable physically and psychologically. They grew up knowing that they were expensive to treat. Some of them had had shortages of treatment or rationing. They were deeply grateful for cryo and the knowledge that their children were not going to die in their twenties but live a long life.

And they were grateful again for concentrate and home treatment. They were dependent on other people's willingness to give blood, on taxpayer s, on continued Government funding of the treatment that kept them alive and healthy. And from 1973, many of them were made dependent on US commercial pharmaceutical companies.

Above all, they were dependent on their doctors

whom they trusted to act in their best interests in the same way that the Society trusted Professor Arthur Bloom and other members of its advisory panel.

These were not relationships between equals and all of these factors are the context for the decisions made by the Society.

and play an active role in society" .

Third, the maintenance of the lives of people with haemophilia would have been less expensive if self-sufficiency had been achieved by 19 77, as Dr Owen and the Medical Research Council said it would have been. As doctors frequently pointed out to Government, if it stopped paying a lot of money for expensive commercial blood products to US pharma, it would recoup the capital cost of rebuilding BPL in a relatively short period of time.

Fourth, had there been better co-operation between the British and Scottish blood services , and any Governmental drive to use the fractionation capacity of Liberton , again, the lives of people with haemophilia would have been less expensive.

And fifth, a person born with haemophilia doesn't come with a set price tag attached. It was within Government's power to control the amount of taxpayers money spent on them . As other Core Participants have pointed out, Government could have limited the amount of money regions were allowed to spend on Factor VIII, or made a decision not to fund prophylaxis or to limit home 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

The next point is Government responsibility.

It's Government's responsibility to consult with a section of the population such as those with a bleeding disorder and any charity that advocates for their rights, but decisions about how to allocate resources are for Government, not for patients and not for little charities that represent patients. What medicines should be licensed for use in the NHS, whether they should be manufactured by the NHS or private companies, whether those companies should be based in the UK or abroad, how much treatment is made available to which patients, and where, these are decisions for Government and for the NHS, not for patients. That was particularly the case in relation to the funding of haemophilia care in the '60s, '70s and '80s, where there was a distinct power imbalance and a patient dependency and vulnerability .

The duty of advising patients about whether they needed a treatment with blood or a blood product, what the choices were, what the treatment recommendation was and why, the risks and benefits, that was the duty of doctors. It was not the duty of the Society.

So why did does the Society support the switch from cryo to concentrate and support importation of US products? Very simply, cryo gave you a long life.

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(6) Pages 21 - 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 2 What home treatment took away, and it's probably not Society offering a hospital assistance with volunteer 3 3 possible for those of us who don't have a bleeding 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. industrial action. 7 In January 1972, the Society republished an 7 If you read The Bulletins of the time, there are 8 editorial from The Practitioner, a journal which is 8 a host of examples, and we've given them in our written 9 primarily aimed at GPs -- which tells you something 9 submissions, of what the Society was doing to try to 10 about how widespread was the state of knowledge at that 10 make treatment available to people across the country, 11 time -- and the editorial talked the reader through the 11 providing home freezers and all sorts of things like 12 work of J Garrott Allen in 1970 which identified the 12 13 fact that commercial blood is riskier than voluntary 13 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 16 people addicted to drugs and alcohol. 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 21 cryoprecipitate or concentrate to meet the needs of 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 23 Society didn't particularly mind what form the treatment 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 Centre Directors who were pressing for permission to do 25 26 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 11 He knew the risks to the bleeding disorder community 11 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. 13 And when he made it possible for US blood products to 13 And the World in Action documentaries were eye 14 come into the country in '73, he committed the 14 opening. So this is a good point to replay part of the 15 Government to self-sufficiency by 1977. 15 second documentary broadcast in December 1975, where 16 That was the aim. The problem was that the aim 16 patients, parents and the Society's Executive Committee 17 wasn't achieved, and there was never a plan B. The 17 were asked for their reactions to the first broadcast, 18 18 which showed how blood was collected in the US on skid Society was concerned at the time that that date was 19 going to be missed. It spoke to Dr Owen at the end of 19 row and the added risks of products. 20 Take it away, please, Lawrence. 20 1975, talked to him about what could be done, about 21 plasmapheresis, the regional structure of BTS and other 21 (Video played) 22 matters, and repeatedly expressed its concern about 22 MS GOLLOP: Sir, I see the time and I'm told that cometh the 23 23 increasing reliance on US commercial concentrates, but time, cometh the Paddington hard stares from the bench. 24 24 So I don't know if this is marmalade sandwich time or nothing changed.

25

REDACTED VERSION

not?

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In his letter to the Archer Inquiry in August 2007.

(7) Pages 25 - 28

1	SIR BRIAN LANGSTAFF: Well, I think it might be a bit early,	1	In January 1983 , Professor Bloom attended
2	if there are, let's say , a few more minutes that you can	2	a Hepatitis Working Party meeting where Dr Craske talked
3	take us up to, say 11.15.	3	about the information he had had from the CDC in
4	MS GOLLOP: Yes, with pleasure.	4	America. At that time, there were ten cases of AIDS in
5	Well, that was December 1975. Probably, one	5	haemophilia A patients in the States, and it seemed to
6	imagines, filmed not long before the Society had its	6	the CDC possible that Factor VIII or other blood
7	meeting with David Owen and talked to him about	7	products might be implicated. That was in January.
8	plasmapheresis and other things that could speed up	8	On 7 March 1983 Dr Evatt at the CDC in the States
9	production in this country.	9	wrote to Professor Bloom and he said this "As you can
10	I want to fast forward, if you'll come with me, to	10	imagine " I think you have to try to imagine
11	1983, and the Society's May advice. Despite its	11	an American accent , which I won't do, but, you know,
12	contacts with civil servants and the doctors on its	12	take yourself back to Atlanta:
13	Medical Advisory Panel, when it came to the two	13	" AIDS is having a major impact on the treatment
14	infections that destroyed so many lives, including the	14	of haemophiliacs here presently. The evolution of the
15	lives of those who you've just seen talking, the Society	15	epidemic is occurring with a frightening pace. We
16	had just as few facts and as little reliable information	16	presently have 13 confirmed haemophiliac patients with
17	about risk as any patient with haemophilia.	17	AIDS in the United States. One of the patients has
18	The Inquiry has produced an impeccable chronology of	18	a Factor IX deficiency, one is bisexual. In addition,
19	the knowledge of risk. When it comes to what the	19	five more highly suspect cases are under investigation.
20	Society knew, it's as important to look at what it	20	The inciden ce rate has been increasing in haemophiliacs
21	didn't know but could have been told, as to what it did	21	and the epidemic curve parlays that of the total
22	know. The Society trusted people with knowledge in the	22	epidemic curve. The first case appeared in
23	NHS and in the Civil Service to share what they knew in	23	a haemophiliac in January 1982, a total of nine were
24	the way that the Society shared what it knew with those	24	reported by December . Of those, eight died in 1982 .
25	people. But this was not an information two-way street . 29	25	I suspect it's a matter of time before you begin to see
1	cases in the United Kingdom. "	1	in March, with its devastating and accurate warning that
2	It is truly shocking to read that letter alongside	2	the epidemic of AIDS amongst people with haemophilia in
3	Professor Bloom's advice to the Society and its members	3	the US was likely to cross the Atlantic and arrive in
4	two months later. It's clear from all of his actions	4	the UK. It will never know why he chose consistently to
5	that Dr Evatt wanted the facts about AIDS and the threat	5	minimise the risk of AIDS. Before this Inquiry, the
6	of AIDS to people with haemophilia to be widely known.	6	Society did not know the extent of his breach of the
7	He was doing everything he could to get the word out.	7	Trust it put in him, and the distress has been
8	This was not, in any sense, a confidential letter.	8	considerable. The Society trusted the doctors providing
9	Professor Bloom could and should have shared it with the	9	it with advice to inform them of the facts and not
10	Society.	10	withhold them even if the facts were difficult to hear.
11	As Mr Snowden pointed out on Tuesday, ten days after	11	It particularly trusted Professor Bloom, who was not
12	the date of that letter, on 17 March 1983, Professor	12	only the UKHCDO chair, but a trusted adviser to
13	Bloom diagnosed AIDS in his own patient with	13	Government at a high level.
14	haemophilia, Kevin Slater , and it was less than two	14	He abused the Society's trust.
15	months later that he gave advice to the Society and its	15	Other doctors have told the Inquiry that there was
16	members that :	16	a lot of confusion. There were lots of conflicting
17	"The cause of AIDS is quite unknown and it has not	17	theories. Things that now seemed clear were not clear
18	been proven to result from transmission of a specific	18	then. But facts are facts and Dr Craske and Professor
19	infected agent in blood products. The number of cases	19	Bloom had the facts about what was happening in the
20	reported in American haemophiliacs is small, and in	20	States and the CDC's working approach to a likely
21	spite of inaccurate statements in the press, we are	21	epidemic. As you said, Sir Brian, during the
22	unaware of any proven case in our own haemophilic	22	presentation on knowledge of risk, the numbers were
23 24	population." The Society will pover know why Professor Bloom did	23	going up. The Society and people with haemophilia were
25	The Society will never know why Professor Bloom did not share with it the letter he received from Dr Evatt	24 25	entitled to know what the numbers were.
25	31		As a follow-up to its "Killer Blood " article in the 32
	REDACTED V	EKSION	~ -

(8) Pages 29 - 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	I 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	on the right-hand column, he tells you really quite	24	He said:
25	a lot:	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
3	"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.
23 24	those selected patients already receiving it."	24	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 PEDACTED VERSION		36

(9) Pages 33 - 36

1	MS GOLLOP: And he doesn't say	1	UKHCDO's guidelines. Not a single doctor in the UK
2	SIR BRIAN LANGSTAFF: But he doesn't say what his view is,	2	contacted the Society to voice any disagreement with the
3	and that has to be balanced, when I come to look at this	3	information it published about AIDS between 1983 and
4	and think about it, with what is reported in The Mail on	4	1985, and many haematologists have given evidence to the
5	Sunday, and for that matter I recall, whether it was	5	Inquiry about the fact that they made The Bulletin
6	that or whether it was the Northern Echo or another	6	available to patients. The Society's belief from '83 to
7	paper, he was recorded saying it was madness to take	7	'85 was that without US concentrates there was not
8	a blood product from a country in the middle of an	8	enough blood product in the UK to treat patients, and
9	epidemic.	9	that if left untreated, patients with severe conditions
10	MS GOLLOP: Yes.	10	would suffer bleeds which would certainly cause damage
11	SIR BRIAN LANGSTAFF: Which would suggest his view, at least	11	to joints. That was the context in which, in
12	at that time, and for the purposes of that report, if	12	September 1983, the Society urged the Government to
13	properly reported, was that it shouldn't be admitted	13	continue to import from the US, which was something that
14	into the country. There we are.	14	the Civil Service had already decided to do in May '83
15	MS GOLLOP: That's right.	15	in any event.
16	And as I said, he is not a haematologist. I think	16	In essence, the treatment advice from Centre
17	he's an immunologist, so far as we know not patient	17	Directors, supported by the Department of Health and all
18	facing. So he wasn't challenged with what to say to	18	parts of the NHS system , did not change until
19	a patient and what to prescribe and that the shortages	19	heat-treated product was universally adopted in 1985.
20	that there were. But the piece that he wrote is more	20	Perhaps the best evidence of how the Society was
21	nuanced and much more helpful than anything than	21	thinking in this crucial period comes from
22	emanated from Professor Bloom.	22	John Prothero , who you heard at the end of that clip and
23	Looking abroad, the risk minimisation measures	23	who, I remind you, died in October 1989, and other
24	unanimously adopted by the World Federation of	24	people with haemophilia in the July 1985 documentary Bad
25	Hemophilia in July 1983 were very similar to the	25	Blood.
	37		38
,	the refer to also are also be a second to ask	4	the first and be unabled the distribution of the
1	I'm going to play some clips in a moment and, to set	1	situation, and he worked hard to achieve acceptance by
2	the scene, by the time this programme went out we're	2	the Government of its moral responsibility towards
3	a decade on from the one we've just looked at, and the	3	people infected by contaminated blood, and he fought for
4	programme started by saying that five people with	4	justice and financial redress for them in the few years
5	haemophilia had died of AIDS in the UK. It discussed	5	left to him between speaking to you then and his death .
6	the numbers of people estimated to be infected in the	6 7	Sir SIR BRIAN LANGSTAFF: That's plainly a convenient moment.
7	UK, and we see Dr Peter Jones saying that , for those		
8 9	infected, there's a 90-95 per cent chance that they're going to be all right , and Dr Savidge saying that the	8 9	So we'll take a break, and we'll come back at 11.45 . So 11.45 .
9 10		10	(11.16 am)
	risk of infecting a partner is about 5 per cent.		(A short break)
11 12	So we will play some of those clips now, and they end with John Prothero.	11 12	(11.45 am)
13		13	SIR BRIAN LANGSTAFF: Yes?
	Thank you, Lawrence.	14	MS GOLLOP: I'm going to make two points in relation to
14 15	(Video played) MS GOLLOP: There may be some Core Participants who have	15	
16		16	hepatitis NANB, as it then was. We've addressed this at
17	a feeling that the Society should have done more to campaign on behalf of people who were infected with HIV	17	some length in our written submissions, and I'm not going to say more than that about this issue now.
18	in the later 1980s, I don't know. For those who do have	18	On Tuesday, Mr Snowden took you to Dr Walford's 1980
19	that feeling, I would strongly recommend that they read	19	•
20	that leeling, I would strongly recommend that they read the statement of Sharon Lewis, Mr Prothero's widow. It	20	memo, where she captured the point, and her recently acquired knowledge , that 90 per cent of post-transfusion
20	talks movingly about his decision to do as much media	21	hepatitis was of the NANB variety— and that it could be
22	work as he could between 1985 and when he died in 1989.	21	rapidly fatal. And, sir, you'll recall her evidence
23	He felt that it was incumbent on him to be open	23	that she escalated a communication of that knowledge up
24	about his infection to combat the stigma of AIDS and to	24	that she escalated a communication of that knowledge up
25	explain the predicament of people who shared his	25	widely and to her superiors . So I won't take you back
-	39 REDACTED V		40
	REDACTED		

(10) Pages 37 - 40

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 whatabout ery. 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	25	SIR BRIAN LANGSTAFF: An example of a non-steroidal
	41		42
1	anti-inflammatory drug is something like ibuprofen . And	1	which could also be fatal, and from which a number of
2	to suggest you're saying, I think, are you that	2	them , in Dr Smithies' words earlier that year , were
3	somebody who takes ibuprofen suffers stigma for	3	undoubtedly going to die.
4	instance, or anything equivalent, is not appropriate?	4	Given Mr John Moore's reaction to what he heard in
5	MS GOLLOP: Not very.	5	the meeting, it is reasonable to think that he would
6	SIR BRIAN LANGSTAFF: No. Thank you.	6	have acted on information about that second killer virus
7	MS GOLLOP: If we keep that in mind you can take it off	7	had he been told about it, as one might think he should
8	the screen . Thank you, Lawrence.	8	have been.
9	If one goes forward eight months or so to	9	The second point, if we fast forward almost a decade
10	3 November 1987, that was the date when the then	10	to the World in Action programmes , which were a valuable
11	minister in the Department, Mr John Moore, had the	11	resource, broadcast in October 1996, with Lord Horam.
12	memorable meeting with the Society and the DHSC in	12	That's HSOC0008602.
13	its written submissions has reproduced some of the	13	The interviews with him are interesting on a number
14	evidence in that regard a memorable meeting with the	14	of counts, not least he gives the line oft repeated by
15	Society at which he was reduced to tears . Because	15	politicians since , "Well, we don't want to spend money
16	attending this meeting were three young men who were	16	on compensation, it would be much better if we used that
17	infected with HIV/AIDS who explained to him their fears	17	money for the wider community", at the same time
18	for themselves and their families . And Mr Roger Moore,	18	refusing to fund recombinant, so not using the money
19	the civil servant, explained that he'd never seen	19	saved by not paying compensation for the benefit of the
20	somebody cry in a meeting before.	20	wider community.
21	The Society would suggest that in a properly run	21	But he's also asked about hepatitis C , as it was
22	health system that was not disjoin ted and siloed, the	22	then called. It was put to him in October 1996 by the
23	Minister, Mr Moore, would have been told in preparation	23	programme that £26 million had been spent on research on
24	for this meeting that infected blood had given people	24	AIDS and just £1 million on researching this is
25	with haemophilia not just AIDS, but also hepatitis NANB,	25	what's put to him "the hepatitis epidemic which
	43 REDACTED V	ERSION	44

(11) Pages 41 - 44

scientists believe could affect more than ten times as many". And Lord Horam's response to that was, " We are not talking about those sort of numbers ". And by that he meant the number of people who were going to be infected with hepatitis C, not the amount of money. One might think that if the fact s that Dr Smithies was aware of and that were known within the Department in 1987 had been recognised publicly at that time, there ought to have been a less dismissive response by the Minister in 199 6, and there would not have been a decade of lost opportunity for properly funded research, learning, and improved patient care. In our written submissions, we've set out a lot of the activity that the Society was engaged on in and around hepatitis C in the 1990s and the campaign that was started, and where that led to eventually after a lot of hard pushing. Sir, I'm going to deal briefly with some miscellaneous matters , and they are litigation , hepatitis C, and the tone that the Society has adopted from time to time over the years. The Society is aware that there is some dismay about the position it took in relation to litigation over HIV infections and its communication to Government of its stance. The documents indicated that when it first moral not legal grounds , and that was an unusual tactic

asked the Government for financial help for people with haemophilia infected with AIDS, the Government's response was that it only pays compensation where there is fault, and it therefore invited infected people with haemophilia to sue. That's there in a document, HSO C0003459, and I'll come on later in these submissions to talk about the Government's response to people who have been affected by some of the Cumberlege medicines and devices, particularly those affected by mesh and sodium valproate, which has been exactly the same. That might be good evidence, you might think, that that was the Government's response in the 1980s, since that remains the Government's response in the 2020s.

Litigation was only open to those who had Legal Aid or enough money to pay lawyers, and that left many people with haemophilia in the middle. They didn't have insufficient money to qualify for Legal Aid and they didn't have enough money to pay privately for representation, so they couldn't bring a claim. The Society was painfully aware that people were dying and it didn't want to use what little energy and time they had left on legal proceedings, so the Society's aim was to get something for everyone infected as quickly as possible.

To do that, it pursued a campaign and later ones on 46

driven by necessity. The Society had had advice from a barrister that any claim it brought on behalf of the charity was unlikely to succeed and, in addition, money was needed within the timescales of the dying, not within the timescales of litigation. That would take years, which people didn't have.

Convincing Government to take this unusual moral case seriously required an explanation of both reasons as to why litigation was not an option. After the Macfarlane £10 million had been secured , the Society pressed on with a second campaign for the same reason: that infected people needed money urgently. The Society notes the witness statement of Lord Frank Field who wrote to you of his own volition, in which he described his work with David Watters to get adequate compensation for infected haemophiliacs so they didn't have to start court action, and the media campaign they collaborated on with the Sunday Times.

In November 1989 , the Government offered a further

In November 1989, the Government offered a further £24 million, including payments of £20,000 each to each person infected or their family of those who had died.

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

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

REDACTED VERSION

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 ground so 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 ve
many of the claimants, appeared before the Archer
Inquiry, and he explained how the settlement had been
achieved at some length. In his evidence, he appeared
appreciative of the Society's efforts to assist the

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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 Co oper".	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	25	It's printing three letters which are a response to
	49		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 has
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 REDACTED	VERSION	52

(13) Pages 49 - 52

1 suffers so far from bleeds." 1 caused it to take a pragmatic approach and to be an 2 2 And in the last paragraph: organisation, so far as it could, that Government could 3 3 "There must be many other haemophiliacs like do business with , when it was possible to do business. 4 [redacted], who feel they cannot approach the Society 4 The brief account of the campaigning work that the 5 because they only have haemophilia." 5 Society did between 1987 and '91 to obtain some 6 Thank you, Lawrence. financial redress for all people with haemophilia $\textbf{SIR BRIAN LANGSTAFF:} \quad \textbf{Just one moment.} \quad \textbf{I wonder if we can}$ 7 infected with HIV as soon as possible illustrates, we 8 redact the name there. submit, how tenacious the Society was and how it didn't 9 Thank you. bow to pressure but kept on campaigning for more after MS GOLLOP: The fact that people felt they had to leave the 10 10 the £20,000 lump sums were paid. And it was capable of 11 Society remains a source of great regret to the charity 11 hard -hitting tactics at times. For example, when 12 12 now. This hurt, and everyone involved in these splits campaigning for the out-of-court settlement in 1990 it 13 was hurt, were a consequence of Government forcing 13 ran an ad campaign. We've not been able to find a picture of this [HSCO0029911], but there is 14 physically injured and psychologically damaged and 14 15 bereaved people to fight for justice and compensation, 15 a description of it in the letter of complaint that was 16 16 and it is partly these experiences in the 1990s that written about the ad campaign to, I think, the BMJ , and 17 cause s the Society to now advocate strongly for a system 17 this is a new document that's been given the number based on swift and fair redress for NHS patients who HSOC0029910. 18 18 19 suffer avoidable harm from a system's breakdown. 19 It had a picture of a child, and the caption read : 20 Lastly, something about saying it right. 20 "Heredity gave him haemophilia, then the NHS gave 21 21 him AIDS." The Society recognises that there are some people 22 who feel that it hasn't been vocal or hard hitting 22 But there was a complaint about that , and I think, 23 23 enough in speaking truth to power, and has, in summary, trying to piece it out, the essence of the complaint was 24 been too deferential. Its focus on achieving the 24 that ad campaign ran in 1990 and people looking at it 25 greatest good for the greatest possible number has 25 might think that the NHS was giving children AIDS in 1 1990 rather than in the 1980s. In any event, a Dr Bird 1 behind, and we listened and we were really moved." 2 wrote a letter of complaint with, it seems, the 2 The Trust and schemes were never adequate, fair or 3 knowledge of some members of the Civil Service, and 3 dignified, but they were the best that the Society would 4 a complaint was made and upheld to the advertising 4 achieve in the face of Government refusal to compensate 5 standards board . 5 people for their injuries. And the Society's efforts on 6 All of that said, generally, the Society has had 6 behalf of the whole community meant that many people who 7 most campaigning success when appealing to the would not otherwise have done so did at least get 8 Government's moral, not legal duty. And the Carpet of 8 something in their lifetime, even though it was not 9 Lilies campaign, which witnesses have said they found 9 enough. 10 moving, relied on personal accounts of the damage done 10 That brings me to the present. And to an apology. 11 to individual lives when Government loses sight of its 11 In 2017, the Society issued an apology as follows 12 12 for its statements during the 1980s, reassuring patients moral obligation to keep a section of the public safe that new factor treatments were safe and to continue 13 and that was a powerful campaign. 13 14 There is some evidence that a quiet explanation of 14 using them . 15 a situation can be more effective than a loud one. 15 "We also lobbied the Government to continue allowing 16 Mr Roger Moore told the Inquiry on 18 January last year 16 the import of products from the USA. 17 that when the Society delegation , which included the 17 "The advice we gave our members was based on 18 three young men with haemophilia infected with HIV came 18 guidance from the Haemophilia Centre Directors 19 to ask the Minister for money, and that was a meeting 19 known as the UKHCDO) and from the Government. The 20 that the Minister went into firmly decid ed that no money 20 leadership and trustees of The Haemophilia Society were

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to the Scandal.

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would be forthcoming, the public servants were expecting

"And what struck us actually was that these were people

anger and a difficult meeting. Mr Roger Moore said,

who had a right to be angry, and they weren't. They

were only concerned about the families that they'd leave

misled and, as a result, unwittingly further contributed

at the time, while well-intentioned and based on expert

advice, have subsequently been shown to be damaging to

"However, we accept that our actions and statements

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1	the community and false. For this, we unreservedly	1	the members they served the same group of doctors and
2	apologise. "	2	such information, advice, choices and treatments as were
3	The submissions of some other infected and affected	3	made available to them all. They suffered or watched
4	Core Participants make it clear that some people feel	4	the children they loved suffer the same appalling
5	that does not go far enough.	5	treatment -induced illnesses and deaths and the Society
6	Now, there's a risk that the Society will sound like	6	doesn't seek not to be judged. It does seek to be
7	the DHSC, and I hope you won't take what I'm now going	7	judged in this light.
8	to say in that same way. The point of the Inquiry for	8	Throughout the Inquiry, the Society and its trustees
9	the Society is multiple, but one of the points is to	9	and staff, many of whom are here today, have made it
10	listen to Sir Brian's objective and fully informed	10	their mission to listen and build bridges while
11	judgment, and that will be an important part of the	11	remaining sensitive to those who need distance from it.
12	learning it does about itself in the past and now.	12	That any member of the bleeding disorder community
13	The Society thinks that it makes sense to reflect on	13	should need such distance remains a source of profound
14	his findings before it says any more than it said in	14	sadness to the Society, and it hopes to be able to
15	2017. It will then have the benefit of something that	15	rebuild trust and work together in the future. The
16	is considered and not the Society marking its own	16	Society would encourage anyone who has not had the
17	homework, but listening to a proper examiner and	17	opportunity to do so to look at Kate Burt's statements,
18	a thought ful dissection of what it got right and what it	18	and those add to the statements made by others who have
19	got wrong.	19	provided evidence to the Society.
20	The Society said this in its written submissions:	20	On behalf of everyone at the charity, Clive Smith,
21	that it would like to say to the Inquiry and to each	21	who you know and who is here, and Kate Burt, who you may
22	person infected and affected by contaminated blood that	22	not know but who is also here please do go and say
23	it was not separate to its members. It was its members.	23	hello. Kate, perhaps you'd like to put your hand in the
24	It was run by patients for patients. Those who formed	24	air.
25	the Executive Committee were individuals who shared with	25	We hear you and we invite you and hope you will feel
	57		58
1	able to talk to us or continue to talk to us. The	1	submissions were supported by the results of a survey of
2	Society hopes that this period of time between now and	2	the membership and their priorities and needs. One of
3	the report's publication and the setting up of the	3	the things that those responding to the Society's survey
4	compensation framework and the legal and psychological	4	were clear about and I think this is something that
5	support structures that need to accompany it could be	5	everybody here will share is the fact that they were
6	a time of healing.	6	very clear that annual payments must continue. The
7	It would like to pay tribute to the infected blood	7	Society was pleased to see that Sir Robert's report is
8	campaigners who have given such a large part of their	8	called Compensation and Redress for the Victims of
9	lives up to the fight for justice. These include the	9	Infected Blood . It agrees with Mr Snowden that language
10	Manor House Group, the Birchgrove Group, Tainted Blood,	10	is important. Use of words such as "hardship" and
11	the contaminated blood campaign, positive women,	11	"recompense", and so on , have led to confusion about the
12	Haemophilia Action UK, Haemophilia Scotland, Haemophilia	12	purpose of monies made available, restrictions on
13	Wales, the Scottish Infected Blood Forum, Haemophilia	13	payments out, and the widespread feeling among
14	Northern Ireland, Friends and Families of Haemophilia	14	applicants that they have had to beg for scraps.
15	Northern Ireland, the Fatherless Generation and	15	It is appropriate for the new financial payments ,
16	Factor 8, alongside many other groups and charities and	16	which will be made as a result of this financial
17	individuals without whom we would never have seen this	17	Inquiry, to be called what they are: compensation.
18	Inquiry take place.	18	The Society repeats what it's called for in
19	We particularly remember those campaigners who did	19	submission to any compensation scheme that's established
20	not live to see the end of the Inquiry. Thank you .	20	and here comes the list :
21	We turn lastly to the future and to recommendations.	21	Anyone who has been significantly affected, having
22	We've covered these extensively in written submissions	22	the right to make a claim ;
23	and I've got written down on paper in front of me	23	To continue existing support schemes alongside
24	a number of lists.	24	a compensation scheme;
25	I will sum marise things as briefly as I can but our 59	25	Compensation to be sufficiently personalised to 60
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1	ensure it reflects the loss and damage served by	1	Inclusion of non-financial elements in the
2	an individual with a framework that should include set	2	compensation package , such as psychological support,
3	tariffs to allow a faster but robust system for those	3	health passporting and Government underwritten life
4	who want to take that route;	4	insurance;
5	A fast track to an emergency payment for those in	5	Financial advice available to all receiving
6	urgent need;	6	compensation;
7	An upfront lump sum to be paid to the infected and	7	An individual assessment by a judge-led pan el with
8	affected community in advance of the full amount;	8	representation from the community, if people choose that
9	A clear, straightforward process which is easy to	9	route; and
10	use;	10	To widen eligibility to include impact from viruses
11	Specialist support for people making applications,	11	or exposure outside the current support schemes, such as
12	particularly where evidence has been lost or destroyed;	12	hepatitis B and vCJD.
13	The claims should be approved on the balance of	13	Accessibility. A significant number of eligib le
14	probabilities with the starting point being that the	14	Society members are older. They don't have smartphones.
15	evidence of the applicant is believed; total parity	15	They don't have tablets or computers , they prefer to get
16	across devolved nations;	16	information on paper in the post and they are
17	A compensation package funded by the Westminster	17	traumatised by their infections. They've had to fill
18	Government because this scandal happened before	18	these forms out time and again and they can't face the
19	devolution;	19	idea that they'll have to do it once more. They don't
20	A system which allows transfer of information from	20	want to have to handle any more administrative tasks
21	supported administrators to schemes to reduce the burden	21	themselves. They need help.
22	on claimants to provide information ;	22	The Inquiry has heard a substantial body of evidence
23	A transparent appeal system;	23	about the hurt caused by the administration of the
24	Previous payments not to be taken into	24	schemes, the future arrangements must be characterised
25	consideration;	25	by respect and compassion.
	61		62
1	UK support sorry, the Society supports the	1	recommendation implementation, the Irish experience,
1 2	UK support sorry, the Society supports the submission by the UKHCDO at paragraph 262 of its closing	1 2	recommendation implementation, the Irish experience, access to current treatment and up-to-date information,
			•
2	submission by the UKHCDO at paragraph 262 of its closing	2	access to current treatment and up-to-date information ,
2	submission by the UKHCDO at paragraph 262 of its closing submissions about compensation for those who have	2	access to current treatment and up-to-date information , ongoing longer term assistance, research on future care
2 3 4	submission by the UKHCDO at paragraph 262 of its closing submissions about compensation for those who have cleared infection with hepatitis C spontaneously	2 3 4	access to current treatment and up-to-date information, ongoing longer term assistance, research on future care and palliative care, training and education, education
2 3 4 5	submission by the UKHCDO at paragraph 262 of its closing submissions about compensation for those who have cleared infection with hepatitis C spontaneously Psychological support. The publication of the	2 3 4 5	access to current treatment and up-to-date information, ongoing longer term assistance, research on future care and palliative care, training and education, education about the scandal itself and an apology and a memorial.
2 3 4 5 6	submission by the UKHCDO at paragraph 262 of its closing submissions about compensation for those who have cleared infection with hepatitis C spontaneously Psychological support. The publication of the Inquiry's report will be the start of a new chapter and	2 3 4 5 6	access to current treatment and up-to-date information, ongoing longer term assistance, research on future care and palliative care, training and education, education about the scandal itself and an apology and a memorial. We repeat all of those and, today, we wish to say
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otherwise of the implementation in the interim , plus of minus a recommendation that the implementation of recommendations in the final report be reviewed by the Cross-Party Health and Social Care Committee on a regular basis with consequent reports to Parliament.

This appears to be what is happening in relation to follow-up of Cumberlege, and when I'm not pinging her about Woman's Hour, I like to ping Ms Richards with entertaining videos of the Select Committee in progress. It's her choice as to which she prefers.

Given the work that Dr Hughes has said she will be doing to follow up redress for those affect ed by the Cumberlege Review Medicines and Devices, the Society hopes it may be possible for this Inquiry to liaise with her about what , if any , infected blood matters may fall within her remit.

Access to current treatment and up-to-date information . The Society endorses paragraph 264 of the UKHCDO closing submissions , and those are about provision of comprehensive care, including a core team of physicians, clinical nurse specialists, psychologists, physiotherapists, lab scientists and social workers -- I'm quoting from their submissions now -- and other experts who address disease related to issues and complications , including he patologist

there are still some rare bleeding disorders where people are reliant on treatment made from human blood and not synthetic treatments -- a choice of treatment to suit lifestyle; and guaranteed access to new therapies including gene therapy; guaranteed access to a multi-disciplinary care package, including psychological services, pain management and physiotherapy; and a quality of access to care including dental treatment and, specifically, endoscopies.

The Society does not ask for its members or for the community the ability to queue jump. It does ask for a recommendation for a health passport that helps the infected and affected communicate their history and their needs quickly, so that they can get the help that they need effectively, without having to go through the whole story from start to finish.

In its written submissions, the Society asks for recommendations on longer term assistance, research on future care and palliative care, training and education, and an apology and memorial. I'm not going to consider those now but they're of equal importance to things I am talking about, and we commend those submissions to you.

On a separate topic, and I shared this information 23 with Ms Richards and Ms Scolding, King's Counsel, 24 yesterday, the Society has very recently received 25

obstetricians, gynaecologists, orthopaedic and dental consultants.

Peer review has identified a persistent lack of a full compliment of multi-disciplinary team members that has gone uncorrected , despite having been identified by previous peer review reports. These deficiencies ultimately arise from inadequate funding of Haemophilia Centre infrastructure.

It would be nice, at a minimum, for your care to be properly funded.

The Irish experience. Brian O'Mahony told this Inquiry that after compensation, the Health Amendment Act card, and knowledgeable, compassionate liaison officers or case managers were the recommendations that have proved most valuable over time, as infected people age and their needs change. That experience should inform, we suggest, the package of measures put into place to support the future welfare of infected and affected people.

We ask you to make a recommendation that all those infected by blood and blood products and all people with a bleeding disorder have access to information relevant to them about their condition and new treatments to be provided through haemophilia centres ; guaranteed access to recombinant -- you may be surprised to hear that

information about hepatitis C and funeral arrangements.

In November last year, it was told about an embalmer who last year refused the touch the body of a man with von Willebrand's disease who was thought to have been infected by blood and had cleared the virus many years before he died last year.

I'm very grateful to the research that's done by the

I'm very grateful to the research that's done by the Leigh Day team. They have uncovered relevant 2018 Health and Safety Executive regulations and it would seem, from this 2022 experience, that those are not as widely known about as they should be.

I am hopeful that Ms Scolding and her solicitors will have more to say about this in due course and I will leave this issue to them .

Turning to public inquiry reform. There's no test for deciding when a public inquiry should be held.

Alan Milburn described the current framework as "pretty non-existen t or woolly". Successive ministers 'denial of requests for a public inquiry were based on their acceptance of the line they were given by the civil servants who were supposed to be helping them, that there was no negligence. And that was even when one minister, Caroline Flint, was in receipt of correspondence from the Society that spelt out the fact that patients had been treated without their consent and

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1 1 experimented upon. Further, that patients were given decision-maker meets victims in person. 2 2 the best treatment available, and anyway, even if they Sir, you've heard evidence from Mr Burnham and 3 3 hadn't, all the lessons had been learned. Mr Jeremy Hunt that both were actively counselled by 4 The history of inadequate co-operation with Archer, 4 civil servants against meeting in person those who were 5 the defensive, insufficiently objective self-sufficiency 5 campaigning for public inquiries. You'll remember 6 report, and the delay in setting up this Inquiry 6 I think -- I think it was Mr Hunt said he'd been 7 evidence that a clear and transparent mechanism for 7 counselled against meeting Nazanin Zaghari-Ratcliffe. 8 making decisions about when to hold a public inquiry, or The Society considers that this sort of a meeting is 9 a non-statutory review, would be extremely helpful if 9 essential. You've heard at least three examples of 10 not required. The Society suggests a recommendation is 10 individuals being profoundly moved and having their 11 made that there be an independent body with the power to 11 views changed by meeting infected and affected people 12 convene a public inquiry -- that would require an 12 John Moore, who we've already discussed, in 1977 13 amendment to the Inquiries Act -- or a recommendation to 13 Mr Hunt in his interaction with Mr Dorricott and his 14 the relevant minister that a public inquiry be held. 14 family; Andy Burnham meeting Eleanor and Fred Bates and 15 Such an independent body could be charged with 15 realising that something was very wrong. There's 16 16 applying transparent criteria to assess the substitute for the decision-maker hearing in person from 17 circumstances in which inquiries or reviews must be 17 those who are suffering and seeking just ice. There 18 held. And it could collate them so that there's 18 shouldn't be a filtering by civil servants. 19 a central repository of recommendations, monitor which 19 It submits that however decisions about whether to 20 recommendations are accepted by Government and how the 20 hold or not hold a public inquiry or statutory review 21 21 implementation works out, and , in appropriate are made in future, an in-person meeting should be 22 circumstances, require inquiry chairs to review such 22 a mandatory part of the decision-making process. 23 23 implementation as there has been. Candour, redress and consent. These three 24 The Society also feels that there is a specific need 24 overlapping concepts, which together form a virtuous 25 to say something about a requirement that the 25 circle, if you remove any one of them, the circle 1 collapses. Jeremy Hunt and Baroness Cumberlege are 1 believe this shift is essential to deliver a safer NHS 2 advocates for a move from our current adversarial system 2 where healthcare professionals have no reason to fear 3 of negligence, where the burden is on you, the infected 3 being candid and telling the truth to their patients." 4 or injured person, to prove not only that something went 4 Her solution was a redress agency : a non-adversarial 5 wrong but that the injury you've suffered was caused by 5 process with determinations based on avoidable harm, 6 what went wrong, and a switch from that to a 6 looking at systemic failings. 7 system, or one of redress for avoidable harm caused by 7 The Government rejected that recommendation 8 systems failure. 8 outright. Its July 2021 response to her report was that those suffering from sodium valproate and pelvic mesh 9 First Do No Harm considered the three medical 9 10 devices and medicines we've looked at. And on the face 10 wanting compensation would have to bring 11 of it, they have no connection to blood. But her 11 proceedings. Exactly the same response it gave to you 12 observations about candour, patient safety, redress and 12 over AIDS in the 1980s and over hepatitis C in the 1990s 13 the need for a cultural shift in the NHS are highly 13 14 relevant. She explained in her report that the duty of 14 One of the reasons it rejected the recommendation 15 candour appears not to have had the desired effect of 15 was, said the Government, that it already has the 16 increasing reporting and disclosure, and we draw the 16 ability to set up support schemes . And the best example 17 Inquiry's attention to paragraphs 2.47 to 2.51 of her 17 that it could come up with was the -- this is how it 18 report. 18 phrases it -- " infected blood support scheme". The only 19 In 2.51 she said this: 19 inference that we can draw from the Government's 20 "We believe that a cultural shift away from blame is 20 reference to that -- and we assume that that is 21 needed to create a healthcare system where people are 21 a reference to EIBSS, and this is a reliance in 22 open and honest. We outline how we feel a no-blame, 22 July 2021 on EIBSS as some sort of model of good 23 23 systems-based approach to delivering redress as practice -- is that the Government actually thinks that 24 24 a substitute for litigation could drive this shift in the infected blood support schemes provided or provide

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paragraphs 2.37 to 2.39 (... [and] Appendix 3). We

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an example of redress done well, so that we don't need 72

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

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and the Government any more than you should have to.

redress is an idea whose time has come. And a further

advantage is that it could be a Centre of Excellence for

financial redress frameworks. The delay that you are

enduring while the cross party working group responds to

A fair, predictable, swiftly responsible system for

First Do No Harm . That records that as late as 2014, the MHRA was maintaining in a report it produced at the request of the Chief Medical Officer that the benefits of mesh outweighed the risks. The Cumberlege Review found that that stance did not fully reflect an understanding of all the risks, and it affirmed the evidence of one campaigner that "the real world evidence 76

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1 1 submissions were due to be filed, it wasn't a matter and patient stories of harms have been overlooked" . 2 2 The Society invites you, sir, to consider the that we were able to deal with in written submissions. 3 3 informed consent section of the Government's response to This is the story. He completed his report and 4 that review and consider whether its actions for 4 delivered the final draft on Christmas Eve 2002. He 5 improvement go far enough. 5 says in his statement that in preparation for his report Publication of this Inquiry's report might also 6 he had a meeting with the Society , and he describes that 7 provide an opportunity to recommend ongoing monitoring 7 as having been extremely helpful. After he delivered 8 of implementation of, for example, the National his report, the Department of Health paid some 9 Institute for Health and Care Excellence's shared 9 consultants -- we don't know who or very much about 10 decision making guideline, and importantly, the extent 10 them -- to amend the report. The amended draft was sent 11 to which patients are routinely made aware that they 11 to clinicians and others -- again, we're not sure who --12 12 have the right to record a discussion with a doctor if for their comments prior to publication. It was not 13 they wish to do so, and the extent to which patients are 13 sent to the Society prior to publication . 14 taking up that opportunity and measure the effect. 14 The Department published the report which it had had 15 A study on those matters could be beneficial. 15 amended without telling Mr Burgin, and Mr Burgin only 16 The Civil Service. A few words about the 16 found out that the report, the original version of which 17 Civil Service, which has not been an ally to those 17 he drafted in 2002, had been published in 2018. 18 18 harmed by infected blood in your search for truth. We'd If you look at his witness statement, which I'll 19 like to say an extended bit, if we might, about the 19 recommend. WITN7485001, he provides a table with 20 Government's 2006 self-sufficiency report. 20 a comparison of what he wrote in 2002 , and the amended 21 21 document was published in 2006. That effectively shows The Society has been dismayed to read the statement 22 of Peter Burgin, the author of the Government 22 that his report was, to use the modern expression, sexed 23 self-sufficiency report -- the original author, I should 23 up by the consultants employed by the Government. The 24 say -- and his statement is dated 15 December 2022. 24 references to the Society appealing to Government not to 25 Since it was made available the day before written 25 ban imports of American imported product despite 78 1 allegedly knowing of the risk of NANB hepatitis were 1 time but, instead, it was possible for Professor Hill to 2 added without his knowledge . 2 cover up his wrongdoing and mislead the original author 3 So far as the Society can see -- we could be wrong 3 of the Government's own internal review and, I say 4 but don't think so -- Mr Burgin's statement to this 4 again, an internal review that it did not share with the 5 Inquiry is the first time that the then professor 5 Society in draft before publishing it. 6 Frank Hill is identified as a contributor to his work. 6 Importantly, we also see history repeating itself. 7 There are footnotes referring to Mr Burgin's interview 7 It was through the good offices of Elisabeth Buggins 8 with Chris Hodgson and his interview with Dr Mark 8 that it was drawn to my attention why it is likely that 9 Winter, and there is a reference to reports from 9 Mr Burgin went to Professor Hill. We don't know and so 10 Dr Hill, but no mention of an interview with him. We 10 it may be that you wish to ask Mr Burgin, I don't know. 11 assume, but we don't know, that when Mr Burgin 11 Mr Kennedy, King's Counsel, has been kind enough to 12 approach ed Dr Hill to assist with the self-sufficiency 12 confirm the facts for me, but in 2002, Professor Hill as he then was, was the chair of the UKHCDO , so it seems 13 report, Dr Hill did not disclose to him the fact that 13 14 a negligence claim brought on behalf of one of his child 14 likely that he was interviewed in his capacity as the 15 patients, whom he had infected with HIV through 15 head of that organisation. 16 contraindicated prescription of Factor VIII rather than 16 One sees alarming parallels with what happened with 17 cryoprecipitate, had been settled at trial in 1992. 17 Professor Bloom, who, as a result of being perhaps the 18 Had the published self-sufficiency report included 18 chair of the UKHCDO, was then asked to sit on almost 19 a list of contributors, the Buggins family, and perhaps 19 every other committee and had a finger in almost every 20 20 the Society, would have had additional grounds to other blood products pie, and we see the damage that 21 challenge it. Had Dr Hill learned any lessons from the 21 that overreliance on one single individual caused. 22 case brought against him and had he been open and honest 22 It's a pity that there wasn't a wider breadth of 23 23 with Mr Burgin, Mr Burgin would have been given direct interviewees, perhaps. It is no fault of Mr Burgin's. 24 evidence that at least one cohort of child patients may 24 He did the best that he could in the circumstances and 25 not have been given the best treatment available at the 25 was not to know otherwise.

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The whole history of that report, its amendment, its publication without any consultation with those who'd contributed to it and an opportunity to comment or correct inaccuracies, is a good illustration of what can happen when there is no enforceable duty on civil servants to behave with candour, openness and transparency. There's no incentive for patient groups to assist Government with report writing if this sort of process is considered appropriate and, worse, patient advocacy charities would be wise to distrust Government or civil servants and not engage .

Outside the NHS and the Care Quality Commission regulated care facilities, there's no mechanism for enforcement of ethical standards in public service.

Lord Evans explained to the Inquiry on 9 November last year, that the Seven Principles are not themselves enforceable in a compliance sense but they give a very clear steer as to the way that individual public servants of any sort should be behaving and, against that background, accountability is pretty meaningless unless you have openness of information, because you can't call somebody to account if the facts are not known.

Well, quite

 $Without \ \ information \ , there's \ \ no \ consent, \ \ no$

accountability, no redress. So the Society, having read Mr Burgin's witness statement, makes the following additional recommendations in addition to the introduction of a formal duty of candour for civil servants: that all Government reports should bear the name of the author; that where individuals have contributed, there should be a list of contributors; and that all contributors should be able to see a report in draft before it is published and given the opportunity to correct inaccuracies.

I move now to my conclusion.

After your report is published, if not before, there will be further work to do. All of the contaminated blood infected and affected must get every penny of compensation to which they're entitled , the support they need to obtain it, quick and smooth access to the treatment and psychological support needed in the future. No one should feel alone or traumatised by the process or unable to cope with more administrative burdens , and the Society will be there for every person within the bleeding disorder community who feels it could help them.

Addressing the devastating impact of the scandal and campaigning for improvements for everyone in the community has been a central part of the Society's work

for the last 40 years. It fully expects that work to continue for the foreseeable future — and after what will be a landmark report.

This vital Inquiry has opened up conversations within families about what happened and that has been welcome. It has also create d need for even more support. For some, the relief of being able to speak truthfully about the past has been a healing process. But for others, and particularly younger generations perhaps who may have a bleeding disorder themselves, discovering that their family history has been based on half-truths and omissions has been difficult to come to terms with. Some people thought they had put a dark and painful time in their life behind them , and are now revisiting the past and finding that it remains traumatic.

Others didn't realise the extent to which their consultant had withheld information from them, and are only now learning about that, and beginning to process such a grave breach of trust. The Society will always be a safe place for anyone in the community impacted by this scandal, a charity that people of any age, gender and race can turn to, confident of a knowledgeable empathetic response, practical help where possible, and informed, robust advocacy if the support they need is

still lacking.

My last words are $% \left(1\right) =\left(1\right) \left(1\right) =\left(1\right) \left(1\right)$ report. He said this:

"People talk too loosely about closure. They fail to recognise that there can be no closure to love and nor should there be for someone you have loved and lost. Furthermore, grief is a journey without a destination. The bereaved travel through a landscape of memories and thoughts of what might have been. It is a journey marked by milestones. Some you seek, some you stumble on. For the families and survivors of Hillsborough, these milestones have included the search for truth, accountability and justice but even these are not the end of the road. They are still travelling , and this report is another step along the way. "

Sir Brian.

SIR BRIAN LANGSTAFF: Thank you, Ms Gollop.

19 We meet again, then, at 2.00 to hear from the 20 UKHCDO. 2.00.

(12.55 pm)

(The Short Adjournment)

23 (2.00 pm)

(Proceedings delayed)

(2.13 pm)

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1	SIR BRIAN LANGSTAFF: Apologie s for the slight delay; there	1	infected and affected , many of whom continue to attend
2	were some technical issues that had to be sorted out.	2	Haemophilia Centres across the UK today .
3	Mr Kennedy .	3	Since its inception, UKHCDO, as an organisation, has
4	Closing Statement by MR KENNEDY KC	4	attempted to support and advocate for people with
5	On behalf of the United Kingdom Haemophilia Centre Doctors'	5	bleeding disorders, and this remains the main focus of
6	Organisation	6	the Organisation today . So whatever factual
7	MR KENNEDY: Sir, thank you. Actually, the apolog y should	7	determination the Inquiry may reach as to the events of
8	come from me because it was my technical difficulties	8	these decades, the reasons for decisions made and taken,
9	which hadn't been sorted out .	9	and any culpability of individuals or organisations, it
10	SIR BRIAN LANGSTAFF: Well, that's very noble of you .	10	should at all times be remembered that the infected and
11	MR KENNEDY: Not at all. It's perhaps a positive place to	11	affected were the innocent victims of events over which
12	start.	12	they had no control.
13	Sir, as you know but others don't, or may not, my	13	Reading the written submissions of the
14	name is Andrew Kennedy. I appear at the Inquiry on	14	Core Participants on behalf of the infected and
15	behalf of the UK Haemophilia Centre Doctors'	15	affected, listening to the oral submissions of my
16	Organisation, instructed by Tan ia Francis at Hempsons.	16	learned friend Mr Snowden and my learned friend
17	Sir, can I start where I started in writing, and	17	Ms Gollop over the last two days, watching the loving
18	just say this: the UKHCDO I'm going to use that	18	and moving tribute to Lee shown on Tuesday only serves
19	abbreviation throughout recognises the tragic events	19	to reinforce this point. The current executive of the
20	of the 1970s, the 1980s and the 199 0s that gave rise to	20	UKHCDO is acutely aware of the suffering of those
21	the need for this Inquiry. The suffering of the	21	innocent victims, and, sir, it is determined to take to
22	infected and affected has been and must remain at the	22	heart the lessons to be learned from your report and to
23	forefront of the work of your Inquiry. That remains the	23	implement fully any recommendations that you may make.
24	case today, as it did at the start.	24	Sir, you designated the Organisation as a Core
25	UKHCDO wishes to express the utmost sympathy for the 85	25	Participant on 19 October 2018, following the acceptance 86
1	of an invitation which the Inquiry, I anticipate on your	1	has collected statistics for the entirety of that
2	direction, had proffered. Hempsons were instructed just	2	period.
3	before Christmas 2018, and I was instructed in the	3	As part of the Inquiry's disclosure exercise, we
4	summer of 2019. Hence neither Hempsons nor I, nor	4	have considered almost 6,000 documents at the request of
5	indeed the UKHCDO, appeared at the opening of the	5	the Inquiry. That is 6,000 documents emanating from the
6	Inquiry on 24 September 2018.	6	Organisation. We have taken no objection to disclosure
7	But present today is Professor Pratima Chowdary, who	7	of any documents, and our comments to the Inquiry have
8	is the current chair of the Organisation and the	8	been confined to proposals for redactions.
9	co-chair of the National Haemophilia Database. She sits	9	As a consequence of that exercise, the Inquiry has
10	towards the back of the room.	10	made available to Core Participants of the order of
11	She is also, sir, as you may recall, the author of	11	2,800 documents which emanate from the UKHCDO. And
12	the NHD statistics report that was provided pursuant to	12	those documents have been available to Core Participants
13	the Inquiry's Rule 9 request.	13	on Relativity.
14	At that opening hearing, my learned friend	14	If you do the simple exercise of trawling through
15	Ms Richards noted that the Organisation had given the	15	who has disclosed what, you will see the UKHCDO's
16	Inquiry unrestricted access to all of its material,	16	disclosure is amongst the largest disclosure of all of
17	physical and electronic, which she described as a huge	17	the Core Participants and , indeed , all of those who have
18	repository of material. Accessing that material has	18	disclosed material to your Inquiry.
19	involved or included the Inquiry's investigators	19	Can I, sir, reiterate , at the outset of my
20	attend ing the National Haemophilia Database in	20	observations, the UKHCDO's gratitude to the Inquiry. As
21	Manchester to inspect its paper archive	21	we explained in paragraph 7 of our submissions, our
22	The volume of material is perhaps unsurprising given	22	written submissions, much of the focus of the
23	that the Organisation spans the entire period of your	23	Organisation during the evidence hearing phase has been
24	Inquiry, so it spans the period from the late 1960s	24	on the preparation of the report to answer the Inquiry's
25	through to today. And as, sir, you know, the database 87	25	Rule 9 request for a UK-wide report on bleeding order 88

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1 (sic) statistics. 1 the exchange of information with NHS Digital and other 2 2 I don't know whether, sir, you've seen the letter organisations, and the reality is the Inquiry has been 3 making the request but effectively the letter said : 3 able to cut through red tape where we have not been able 4 Please could you provide an equivalent report to the 4 to. That has allowed us to complete the database, if 5 report that you provided to the Penrose Inquiry but for 5 I can put it like that, with up-to-date information . 6 the entirety of the UK. particularly about cause of death. 7 For the sake of the transcript, and as I say, the 7 Sir, as we say in our written submissions , towards 8 author of which is Professor Chowdary, the report is to 8 the end at paragraph 276, our suggestion is that the 9 be found at WITN38226016. 9 report demonstrates the value of the database. 10 This was a very substantial piece of work. Again 10 I acknowledge that some have expressed concerns that 11 I say, unsurprising, given that the period that we 11 their data is held, whether by the database or at all, 12 12 looked at was one of more than 50 years , from 1969 to but we would hope that , having now seen the report, 13 2020, that the Inquiry's request was that the data be 13 those who have been concerned can now see the merit or 14 set out on an annual basis, disaggregated, as the 14 at least some merit in that data being collected and 15 expression used in the letter, to centre, and specifying 15 being made available. 16 16 the amount of each product used. Sir, we addressed issues of consent to the holding 17 Those who have read the report and, more 17 of data and access to data in our written submissions in 18 particularly, been through the spreadsheets, will 18 paragraphs 53 to 64. I do not propose, unless you wish 19 appreciate the extent of the exercise 19 me to, to repeat those now, but I would direct anybody 20 Sir, whilst much of the data -- and this is my 20 to those paragraphs but, more particularly, to what is 21 gratitude on behalf of the Organisation -- was already 21 said on the UKHCDO website about addressing 22 computerised, some of it was not, and the Organisation 22 information -- sorry, what is said on the UKHCDO website 23 23 is grateful to the Inquiry for the assistance it's been about addressing the information that is held and how to 24 able to provide to enable the final digitisation of the 24 go about accessing it. 25 database, and perhaps more particularly for facilitating 25 We believe that the database is without rival across 90 1 the world. Sir, we referenced in our written 1 evidence or a combination of the two 2 submissions European research , including about the 2 The first sought clarification of information held 3 incidence of such databases, that showed in 2008 only 3 by the database concerning a relative of a witness who 4 a bare majority of European countries had a national 4 had given a statement to the Inquiry. It was a very 5 haemophilia patient registry , as it was referred to in 5 detailed enquiry in relation to "Why does it say [X] 6 that paper. 6 when I believe [Y]?" 7 By that stage, the database was entering early I don't wish in any way to diminish the import of 8 middle age. We suggest that the value is underscored by 8 the request but it was confined, as I say , to a detailed 9 9 the work undertaken by your statistics expert group, and enquiry about the entry for one patient on the database. 10 in particular, the complex modelling that it had to 10 The second request that we had related to criticisms 11 undertake to make an assessment of the impact of 11 made by Jason Evans, primarily about the legality of 12 infected blood on transfusion recipients , for whom there 12 data held on the database and information sharing, and also the criticisms that are set out in the Tainted 13 13 14 sir, all one has to do is to compare the accuracy of 14 Blood document. 15 figures that the group provided for HCV and HIV 15 Those were the two Rule 9 requests that we received 16 infections, and also for deaths, for those with bleeding 16 in addition to that for the statistics report. Sir, 17 disorders, against those for people with blood 17 a number of clinicians have provided statements to the 18 transfusions, and you'll recall the breadth or the range 18 Inquiry about UKHCDO. SIR BRIAN LANGSTAFF: I think the orchestra are leaving. 19 of possible accurate answers to the latter. 19 MR KENNEDY: I was going to recount a story about that but 20 20 Sir, can I then just say one or two more words about 21 the balance of our involvement with the Inquiry. Aside 21 I won't do it now, it's not the time or place .

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from the Rule 9 request for the statistics report,

UKHCDO received two further Rule 9 requests. They both

emanated from criticisms that had been made by witnesses

who had either provided written statements or given oral

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I was saying a number of clinicians had provided

statements about UKHCDO or their involvement with the

Organisation, and some of those witnesses have given

evidence to the Inquiry. Each has done so in a personal

1 capacity in this sense: their statements were prepared 1 in effect, the sum of its individual members. It does 2 2 by their defence organisations or by, we anticipate. not have a corporate identity or a corporate memory in 3 3 their employing trusts. The UKHCDO legal team was not the same way that perhaps an NHS Trust might have. 4 involved in the preparation of the statements, and we 4 Second, the current executive, and indeed membership, 5 were told when we enquired about the Rule 9 requests 5 self-evidently, is not made up of the same individuals 6 that they were confidential to the clinician. as the membership at the material time in the 1970s, 7 Sir, the written evidence you have received in '80s and '90s and, much as the Inquiry has faced 8 relation to the UKHCDO has been prepared without any challenges in obtaining accurate and reliable evidence 9 input from the UKHCDO legal team. Now , that may well be 9 in relation to matters which occurred over 40 years ago, 10 a good thing; it certainly would answer any suggestion 10 the UKHCDO's membership and executive is not in 11 party line taken by the Organisation. 11 a position to comment definitively on events about which 12 12 But it follows also from that that the witnesses who they have little or no firsthand knowledge. 13 have given evidence before you, none of those have been. 13 I underscore the point I made to you a moment ago, 14 as my learned friend Ms Grey put it yesterday, supported 14 sir, that those who have spoken about the UKHCDO have 15 by, in this case, the UKHCDO legal team. 15 done so with their, if I can put it likely this, 16 16 We explain in our written submissions that the clinician hats on rather than their UKHCDO hats on. 17 current executive of the Organisation has concluded that 17 Perhaps more importantly than either of those two 18 18 it should not take a position on the issues that you points is this: the current executive and the wider 19 have to decide or the factual findings that you should 19 membership of the Organisation have a continuing 20 make. I am conscious that there was disquiet yesterday 20 therapeutic and professional relationship with some of 21 when that stance was explored with my learned friend 21 the infected and affected, and with others with 22 Ms Grey, and I set out, if I may, the rationale for that 22 haemophilia. It is felt that for the Organisation to 23 23 position. take a position as to the merits of the issues with 24 There are three points. First, the UKHCDO is 24 which the Inquiry is concerned would be potentially to 25 a professional membership society. The Organisation is 25 compromise that continuing therapeutic relationship. 93 94 1 Sir, it is for those reasons that is the rationale, 1 They said this: 2 as I put it, for the stance that we have taken of not 2 "The first and fundamental point is that it is now 3 seeking to comment on what findings you should make or 3 potentially impossible to trace over the decisions of 4 indeed not make 4 the past ..." 5 Sir, can I, acknowledging what I have just said, 5 They give the example in relation to the risk of 6 just draw your attention to one or two matters , with the 6 AIDS in the 1980s: 7 greatest respect, about the fact-finding exercise, and 7 "... without being influenced by the awareness of 8 I do so conscious of what my learned friend Mr Snowden 8 what comes next. Rather like trying to retrace one's 9 9 said yesterday about the passage of time. I don't think way to the centre of a maze , which has been successful 10 it can be said of the Organisation that we can't blame 10 negotiated, the route on the second journey into the 11 something which is -- lay the blame for something which 11 maze will be influenced consciously or subconsciously by 12 12 the previous successful trip or roadmap. Less weight or is our fault, and I'm very conscious of the point that 13 he made to you, with which I agree, which is that you 13 attention given is to blind alleys or false starts 14 are well familiar with dealing with issues of fading 14 seemed appropriate routes , even promising ones at the 15 memories, so I say no more about that. 15 time, but were later shown to be mistaken. 16 But, sir, the passage of time -- or rather with the 16 exploring them is more likely to be discounted. Equally 17 passage of time come developments in practice 17 it may be harder to give credence or weight to the 18 changes in prevailing standards. The Inquiry may wish 18 intentions and plans of those involved at the time when 19 to acknowledge and take that point into 19 later shown to be flawed."

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paragraph 1.24.

I would then , if I may , respectfully adopt what the

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Department of Health legal team said about guarding

against hindsight bias. I don't know if you recall it,

sir, or others recall it, we would underscore the maze

analogy, which they drew in their submissions at

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Again, sir, I acknowledge that is something you will

be familiar with overcoming, but I just, as I say,

career when I dealt with quite a lot of industrial

SIR BRIAN LANGSTAFF: Well, it used to be, early in my

injury accidents in practice, I know some advocates

endorse that point.

1	would say to a judge , "Well, look at the changes there	1	a small "p" rather than a large "P" from the
2	have been in practice now as a result of this accident.	2	presentations that CTI have produced, of the minutes of
3	That should have been done beforehand ", and it was never	3	the meetings of UKHCDO and some of its working parties
4	a proper answer.	4	to assist the Inquiry in this sense: by placing all that
5	MR KENNEDY: No.	5	material in chronological order and in one document ,
6	SIR BRIAN LANGSTAFF: It might indicate, in some	6	with the guide to where it is to be found on Relativity.
7	circumstances, depending on the context, that more could	7	We hope it is more than just a chronology. It was,
8	have been done, but it might not .	8	however, consciously a summary and nothing, sir, should
9	MR KENNEDY: It wasn't a complete answer .	9	be taken from the amount of detail or the lack of detail
10	SIR BRIAN LANGSTAFF: No.	10	with which we have dealt with events in that part of our
11	MR KENNEDY: No.	11	written closing.
12	SIR BRIAN LANGSTAFF: So it's a question of context, and	12	It is intended to be neutral. It includes material
13	context, I think, is knowing, as best one can, it is the	13	that is both positive and negative , so far as the
14	past and the past , as someone has said , is a foreign	14	Organisation is concerned. So if it speaks , for
15	country. But it's understanding, trying to understand ,	15	instance, to the preference expressed by directors in
16	as best one can , what the context was and bear in mind	16	the early 1970s for imported concentrates. It speaks
17	what, at the time, the context should have been , if it	17	equally to the views of the directors and the
18	wasn't.	18	Organisation that self-sufficiency had to be achieved
19	MR KENNEDY: Indeed. Indeed.	19	and had to be achieved soon , and we've endeavoured to
20	SIR BRIAN LANGSTAFF: It's a complex judgement.	20	strike a balance as best we can.
21	MR KENNEDY: It is, indeed. We refer to it as context in	21	My learned friend , Mr Snowden also said that we'd
22	our submissions and indeed that is what it is.	22	said nothing about the Heathrow meeting in January 1983.
23	Sir, I say this with a little trepidation, given	23	He is correct. I simply recorded that it had happened.
24	what Mr Snowden said on Tuesday , we undertook the	24	That was for the simple reason that we believe it was
25	exercise of setting out a form of presentation I use	25	an event that the Inquiry had considered in depth, and
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4	the cignificance of which was largely phyloge	4	and the Organization haliques that this is one of the
1	the significance of which was largely obvious.	1	and the Organisation believes that this is one of the
2	We simply, therefore, place the meeting in its	2 3	earliest examples of professional peer review in the NHS.
3	chronological context with other meetings of the		
4	Organisation, so as to permit you, sir, to take	4	Sir, to give a chronological landmark, if I can put
5	a longitudinal view.	5 6	it like that, the National Institute for Clinical
6	Sir, we set out the origins of the Organisation in		Excellence, what we know as NICE , now called the
7	our written submissions. We explained that in the	7	National Institute for Health and Care Excellence, that
8	absence of direct evidence we've drawn information from	8	was set up in 1999. Now it's not a direct comparator
9	material available on Relativity, some of which is from	9	but maybe it will give you a chronological landmark. So
10	our archive. I don't propose , you'll be glad to hear ,	10	it's a little bit short of a decade behind the
11	to cover that ground orally. I will just say of the	11	introduction of peer review by the Organisation.
12	Organisation: whilst we acknowledge that criticisms have	12	Sir, the Organisation aims to consider the
13	been and may in the future be made of the Organisation	13	contemporaneous uncertainties in managing individuals
14	and how it has acted in the past, and that it has been	14	with bleeding disorders, to enhance the understanding of
15	slow to act in the past, there is countervailing	15	inherited bleeding disorders and their management, and
16	evidence that shows that the Organisation has at times	16	to improve the quality of care for this group of people.
17	been a leader and not a follower.	17	As is typical of such professional societies, the
18	I've mentioned in my submissions the database.	18	UKHCDO seeks to provide guidance where reliable evidence
19	I would also mention its attitude towards the promotion	19	is available. In the absence of good evidence it
20	of comprehensive care. And again, sir, you may recall	20	provides a forum for examining existing information ,
21	that the 2008 European Inquiry stressed the importance	21	exchanging opinions and experience, and articulating
22	of comprehensive care.	22	a consensus on the potential approaches to deal with
23	I would add a third point, and it is this: it is the	23	challenges reported in routine clinical practice . It
24 25	introduction of professional peer review in Scotland and	24 25	encourages collaboration, both nationally and
	Ireland in 1991, and England and Wales in 1992 and 1993,	75	internationally.

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1	As we have pointed out in our written submissions.	1	those at its head or by the largest Haemophilia Centres.
2	sir, these deliberations also permit the identification	2	Before looking at that briefly, can I just observe this:
3	of unmet needs or service deficiencies.	3	from the outset, so that's back to Rosemary Biggs in
4	Since its inception, the membership of the	4	1968/9, and the early meetings of the 1970s, the
5	Organisation has been drawn from all four home nations.	5	Department of Health, then the Ministry of Health, and
6	This continues to be the case today, despite devolution.	6	the blood transfusion centres, were regular attenders at
7	Hence the Organisation seeks to improve the quality of	7	UKHCDO meetings, and the Department continued to be an
8	care of people with bleeding disorders, irrespective of	8	attender at meetings. And I've, I hope, captured that
9	the policies and priorities of their national	9	in that part of our written submissions .
10	commissioners and providers.	10	Similarly, The Haemophilia Society was an early and
11	That said, as we say in our written submission,	11	regular attender at the annual general meeting. The
12	healthcare policy is the province of the UK Department	12	first record that I can identify is 1 November 1974, the
13	of Health , NHS commissioners and other designated bodies	13	Relativity reference is HCDO0001 017, but again we
14		14	
15	and their equivalents in the devolved nations.	15	capture that in our written closing.
16	We seek to influence healthcare in clinical policies	16	My learned friend , on behalf of the Leigh Day Core
	through interactions with members of these organisations		Participants, and I hope they'll forgive me if I give
17	and other national and regional bodies. But as we	17	them that name, described the Organisation as
18	explain in our written submissions, we don't have a role	18	a "voluntary and unincorporated association". That is
19	in the accreditation or ongoing assessment of doctors.	19	SUBS0000059_210 at paragraph 26, where my learned
20	That falls to the General Medical Council and the Royal	20	friends wrote this:
21	Colleges .	21	"It proved to be significant that this de facto
22	Sir, can I address one or two points arising from	22	leadership organisation was a voluntary and
23	the submissions of other Core Participants, and then	23	unincorporated association , essentially dominated by the
24	I have some comments to make about recommendations. One recurring theme was that UKHCDO was dominated by	24	largest and most influential centres."
25	101	25	We certainly would agree with the first part of that 102
	14.		
1	proposition, in other words a voluntary and	1	organisations such as this, it is often the case that
2	unincorporated organisation, and that remained the case,	2	one personality or one or more personalities may
3	sir, as you will be aware, certainly up until the early	3	dominate. But whether the larger centres
4	'90s with charitable status and the limited company.	4	inappropriately dominate d, as I say, sir, is something
5	So that was the status for much of the period you're	5	you may want to wrestle with. You may bear in mind that
6	concerned with. Whether, on the other hand, it was	6	their directors will have brought greater experience , if
7	and I would add "inappropriately " so whether it was	7	not greater expertise , greater experience coming from
8	inappropriately dominate d by the largest and most	8	treatment of a greater number of patients
9	influential centres is a matter, sir, that you will have	9	My learned friends on behalf of the Thompsons Core
10	to wrestle with. I just make this observation: we've	10	Participants make a similar point. They say the UKHCDO
11	set out how the Organisation in its meetings changed	11	was a club dominated by those at its head. In their
12	over time in paragraph 66 and following of our written	12	submissions, which is SUBS0000064_0247, at
13	closing and you will have seen that , for much of the	13	paragraph 4.55, they said this:
14	period, the Reference Centre Directors , as they were	14	"In the evidence heard by the Inquiry from
15	called, met at least biannually and all the directors	15	Government Ministers, the 'clinical freedom' [which they
16	once a year.	16	put in inverted commas] which was championed as a means
17	It's perhaps unsurprising, if the directors of the	17	of the Government evading ultimate responsibility when
18	larger centres played a greater role for the simple	18	things went wrong in the medical sphere. In fact, given
19		19	
20	reason that they attended meetings three or perhaps four times a year, whereas the directors of Haemophilia	20	that the individual haemophilia clinicians were bound by the diktats of this group, what is more, Dr Winter
21 22	Centres or associate centres only once a year.	21 22	described the group as being a form of club where the
	That is for understandable reasons : a meeting of 10		views of the few at the top predominated. This approach
23	or 12 is easier to organise , certainly in pre- Zoom days,	23	to centralised decision making by a few core individuals
24 25	than a meeting of 78.	24 25	had important ramifications for the care of haemophilia
25	We know from personal experience that , in 103	25	patients generally, but also as for the formulation of 104
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(26) Pages 101 - 104

1 policy in the care of haemophiliacs in Scotland in 1 a director. 2 2 particular." Forgive me, I paraphrase her final question. But 3 3 I just say this: the observation of "dominated by Dr Winter's answer is, we would suggest, informative. 4 those at the top " we leave to you but we would just , 4 He says: 5 with respect, correct what my learned friends say when 5 "I don't agree with that. I think we should state they attribute that expression to Dr Winter. 6 6 UKHCDO was generally regard ed by the other haemophilia 7 Lawrence, if we can just bring up Dr Winter's 7 societies and doctors and other countries as 8 evidence. He gave evidence on 1 October 2020 and my being a model of its kind. There isn't really any other 9 learned friend, Ms Richards asked Dr Winter the question 9 country where haemophilia doctors came together and 10 at the bottom of page 114 of the transcript. Thank you, 10 collaborated to such an extent that every patient with 11 Lawrence. 11 an inherited blood disease in the country was 12 12 She said: registered, we knew the number of patients with the 13 "Can I ask you one further question about UKHCDO, 13 condition, we knew the severity of the condition, we 14 not at any one point in time, but in the knowledge that 14 knew whether they had an inhibitor, we knew whether they 15 you are about to become a member, in the end of 1983, 15 were on home treatment, we knew whether they were alive 16 16 when you became a director in Kent. or dead. No other [patient] had information like this. 17 "Professor Savidge , who you obviously dealt with 17 And every time you went to a World Federation meeting, 18 quite extensively over the following months and years, 18 people would say , you know, your system you have in the 19 in his evidence to the Archer Inquiry was very much 19 UK is light years [I suspect he means 'ahead'] of what 20 critical of UKHCDO. He said it was run pretty much as 20 we have in our country. We have nothing like 21 21 "Then, in addition to that, as we've seen already, a club by the ten or so main players , and there was 22 something of an information vacuum for directors in 22 it was a very active organisation , in addition to all 23 23 the day-to-day work we were doing . At any one time , particular of smaller centres." 24 She asked him whether he would agree with that, 24 there would be six, seven, eight working parties in 25 whether that was his experience once he became 25 specialist areas. So I thought the UKHCDO was a very 105 1 good thing. Of course , there were personalities 1 forgive me, the DHSC mention ed the evidence of 2 involved, of which Professor Savidge was a large one." 2 Dr Walford, that the guidance issued in June of 1983 was 3 Thank you, Lawrence. 3 weak because it was advisory rather than mandatory. 4 Sir, my learned friend Ms Gollop on behalf of 4 And, sir, perhaps I should just fill in the dots 5 The Haemophilia Society, says in her written submissions 5 So the guidance that I'm referring to is that of 6 on a number of occasions that the UKHCDO was the most 6 24 June 1983 . I'm assuming that everybody is so 7 authoritative body or voice in the UK. invested in the detail of this case that they will know 8 We suggest that is neither surprising nor sinister. 8 what I'm referring to, but it was the first guidance 9 Certainly objectively. It was formed of most if not all 9 that came from UKHCDO that bore in mind the AIDS -- bore 10 doctors treating haemophilia on a regular basis. That 10 in mind AIDS . 11 is, it was a group sharing a common interest or concern 11 In terms of what the Organisation could and could 12 in the treatment of a discrete disease. And we would 12 not achieve, we would agree with Leigh Day -- the Leigh 13 anticipate that the same might be said of a number of 13 Day Core Participants -- when they say that we could not 14 equivalent professional societies, both then and now, 14 have granted ourselves -- I paraphrase -- could not have 15 where the number of patients suffering the disease is 15 granted ourselves a power to make -- forgive me -- to 16 such that it would not support more than one 16 make binding clinical recommendations 17 professional society. 17 That is SUBS0000059_0212 at paragraph 33. 18 That said -- this is my comment objectively -- that 18 And we agree with what is self-evidently implicit in 19 said, we would entirely accept that with that status 19 that statement, which is that we didn't have that power. 20 20 comes responsibility, and the Inquiry will have to Plainly, sir, it will be a matter for you whether 21 address whether the Organisation did or did not 21 the guidance that was promulgated should have been 22 discharge that responsibility. 22 expressed in stronger terms. Both should have been 23 23 Another point that is made is that the guidance that expressed in stronger terms, and should have been more 24 24 was issued by the Organisation was not mandatory. In extensive or more expansive. But we would simply say to 25 particular -- and it's said by the DHSC -sorry. 25 you, sir, that the Organisation was not in a position to

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1 1 Participants suggest that the Organisation should have mandate or direct practice, the practice or treatment 2 2 provided by clinicians. sought to put -- forgive me -- should have asked for 3 3 There are perhaps two relevant points to make. itself to be put on a statutory footing. We're not 4 First, we had no power to do so. But we also had no 4 clear how that could have been achieved but it seems to 5 means of enforcing a direction. And if you, sir --5 us that that would have had two main drawbacks. First, 6 I can see you perhaps mentally posing yourself the Organisation would have become simply another arm of 7 a question. If you look , for instance , at the guidance 7 Government or the Department , and it's unclear to us 8 issued in 1997 in relation to recombinant products, and 8 where the Organisation would have sat, for instance, in 9 I touch on that in my written closing, even that 9 relation to a body such as the CSM. 10 may be said it goes further than what was said in 1983. 10 There is also evidence that you have seen, sir, and 11 but even that doesn't say, "You must do this". It says, 11 heard, that at times the Government didn't listen to the 12 "You should". 12 Organisation anyway. Perhaps more significantly from 13 So it seems to us that the question is whether the 13 the Organisation's perspective, had that happen 14 guidance should have been expressed more strongly rather 14 would have lost its independence and it would have 15 than it should have been set out in mandatory terms. 15 significantly curtailed, we would suggest, its ability 16 16 to speak on behalf of those with bleeding disorders and We would also just invite you to bear in mind that 17 if this guidance was to be expressed in mandatory terms, 17 indeed those treating them. 18 18 it would have had to apply not just to Haemophilia I'm conscious of time. I'm moving slower than I'd 19 Centres but to any hospital that might treat 19 anticipated, but there are three examples and I will 20 a haemophiliac and , indeed , arguably across the board , 20 take them very briefly : one is self-sufficiency ; two is, 21 because it would be relevant to those receiving blood 21 as I mentioned earlier, recombinant products, where the 22 transfusion s. So we would respectfully suggest that , if 22 Department's response was "We're not going to sign off 23 23 your guidance because" -- well, I'll leave others to mandatory guidance was required, it needed to come from 24 a body with greater and broader authority than UKHCDO. 24 answer the "because"; and the third example is what 25 I think acknowledging that point, the Leigh Day Core 25 happened in relation to variant CJD, and what the 109 110 1 Organisation said about the use of domestic blood at the 1 learned friends put it , to shut the story down. 2 time of the variant CJD concerns. 2 I deal with, if I may -- jumping on to something 3 Can I deal then with one matter which arises in the 3 that my learned friends for the Milners' submissions made by the Collins 'Core Participants. Core Participants say . The reference to their 4 4 5 It's a short point, and it's just this: when discussing 5 submissions is SUBS0000005_0117 , at paragraph 350. It's 6 the issue of candour, albeit in the context of a chapter 6 just a correction of a Relativity reference but they say 7 on ministers, but in a chapter that is -- a proposition this, they say: 8 that is repeated in the chapter on clinicians, my 8 "Nevertheless by January 1983 the issue of AIDS 9 learned friends say of the article that Dr Peter Jones 9 remained a footnote or afterthought in the minute of the 10 wrote to the Press Council -- and sir, if it helps, 10 meeting of the UKHCDO which took place on 8 January that 11 I can ask Lawrence to bring that up. 11 year. The directors noted that AIDS was similar in its 12 So this is PJON -- sir, this is the , forgive me, 12 epidemiology to HPV and that the working party ought to 13 enquire about the likely transmission of the disease article letter. So this is the letter that 13 14 Dr Peter Jones wrote on 6 May 1983, complaining about an 14 through blood and blood products. 15 article that had been in The Mail on Sunday five days 15 "In our submission, this lack of recognition of the 16 before. 16 severity of the risk posed is characteristic of the 17 My learned friends say that Dr Jones was writing on 17 UKHCDO's lethargic approach to addressing emergency 18 behalf of UKHCDO. And it's that latter part which 18 threats." 19 concerns me. There is , of course , a legitimate question 19 Sir, the short point is this: that "footnote or 20 20 for you to address as to whether Dr Jones was right afterthought ", as they put it, was not 8 January 1983. 21 to -- sorry, was correct to write in the terms that he 21 It was a meeting that -- the Relativity reference is 22 22 this: $\mbox{HCDO0000003}_058$. That is a Relativity reference did. And it may be -- I accept maybe that others within 23 23 the Organisation shared the sentiments that he expressed to a meeting -- sorry , the minutes of a meeting of 24 24 in this letter. But we're unclear whether it is correct the -- sorry, of the Hepatitis Working Party on 25 to say that this was the Organisation seeking, as my 25 13 September 1982. And the date may be important for

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There are similar examples that we cite in our

submissions, written submissions at paragraph 24. For

instance, again, Dr Biggs's review of haemophilia

the allegation of lethargy , but you will appreciate that 1 in its entirety, but I think we can all recognise 2 comes about the midpoint between the two CDC letters significant changes. Today's patient is much more 3 of 1982. A meeting of the Hepatitis Working Party took prepared to question his or her doctor than the patient place on 19 January 1983, and it's apparent from the 4 in the 1960s, '70s or '80s. meetings -- sorry $% \left(1\right) =\left(1\right) +\left(1\right) +$ 5 Moreover, we would suggest that in reality, with the was one of the central issues that was addressed. 6 increasing use of evidence-based medicine, the Sir, that we address in our submissions at acknowledgement that departure from guidance needs to be paragraph 124. justified and informed consent sought, the advent of Sir, two further matters which arise from 9 organisations such as NICE means that clinical submissions. One is this: it relates to the issue of 10 freedom -- or rather there is less clinical freedom now clinical freedom. A number of the Core Participants 11 than there was 30 years ago. Moreover, we would caution 12 12 have warned or cautioned of the perils of unfettered reaching conclusions about clinical freedom based upon 13 clinical freedom, and some have hinted to a suggestion 13 what I might refer to as a small sample size, so having that there is need for a review and qualification of 14 looked at one discrete area of medicine, and equally, clinical freedom. 15 caution recognising , as one of your expert groups 16 16 Can we just say this in response to that. As we recognised, that clinical freedom permits incremental said a moment ago, sir, the practice of medicine has 17 change in practice. changed substantially over the years with which you are 18 Then, sir, if I can just turn briefly to research. concerned. There have been extraordinary advances in 19 Again, much has been written and said about research. 20 treatment, both surgical and medical. 20 The Organisation would accept that , during the relevant 21 period, clinicians who were UKHCDO members conducted There has, we would suggest, also been a change in 22 what we might term the "deference" that a patient has 22 studies in the sense of clinical trials or what might be 23 for his or her doctor. There are , legitimate no doubt, 23 referred to as interventional research. We would also 24 criticisms of a paternalistic attitude in the 1970s, and 24 accept that these studies were often discussed at 25 indeed later. We don't say that that has been abolished 25 meetings of the Organisation , and we have referred in 113 114 our written submission to discussion of , for instance, 1 treatment 1969 to '7 4 and equivalent exercises trial protocols. 2 undertaken by Dr Rizza, during later periods. I just wish to make this clear on behalf of the 3 Sir, I'm going to turn if I may briefly to Organisation. That research was not conducted by 4 recommendations. I've been going for an hour, I would UKHCDO. It was conducted by people who were members of 5 propose, subject to your views, that I press on and the UKHCDO. The Organisation has confined its 6 finish. I don't think I will be more than another ten research -- so that is research that is published in its 7 or 15 minutes. SIR BRIAN LANGSTAFF: Then by all means do so. name -- to observational studies, that I'm going to 8 MR KENNEDY: I should just add that I'm about the worst refer to as "observational studies". It's referred to 9 10 elsewhere perhaps as "audit service evaluation" or 10 judge of time. SIR BRIAN LANGSTAFF: Well, you won't be in a minority of "observational research" 11 12 That observational research is conducted 12 one in that respect. MR KENNEDY: I can hear my learned friend Ms Richards making 13 involves, a retrospective study primarily of data collected as part of the annual returns. 14 an aside which may indicate that she and I are in the 15 mentioned some examples of this, and again , conscious of 15 same boat. 16 time, the earliest , I think , example of this is 16 SIR BRIAN LANGSTAFF: I couldn't possibly comment. MR KENNEDY: I'm not going to -- we've set out our views on 17 Dr Biggs's study at the beginning of the 1970s, of the 17 18 inciden ce of jaundice and antibodies or inhibitors which 18 recommendations in writing. I'm not going to go through 19 was published in 1974. That is PRSE0002554, and if we 19 all of what we've said. I just want to touch on four look -- if that is looked up, you will see that she 20 points, two of which as will be apparent when I come to writes on behalf of , I think , she says the 37 directors 21 them -- forgive me, I think it's five points , two or 22 of haemophilia centres. 22 three of which are of particular interest to the

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organisation. I just say a word about compensation.

We recognise that it may rightly be said that

compensation is no business of UKHCDO. But I would just 116

1	say this : adopting the approach that my learned friend	1	Medicines Unit resulted in a very significant saving in
2	Mr Snowden took on Tuesday of identifying matters which	2	the unit cost of medicines due to UK-wide procurement.
3	perhaps the lawyers weren't concerned about but the	3	It had been hoped that some of the savings generated
4	clients were and he identified natural clearers as	4	could be used to support the development of
5	being falling into that category, and I identify that	5	comprehensive care. Sa dly, that was not the case
6	too. Now, that was something that was specifically	6	that has not proved the case.
7	mentioned to me when we were providing our setting	7	At 264, we point out that the provision of
8	out our response to recommendations. And so what we	8	comprehensive care is the first step to becoming
9	would say or rather what the Organisation would say is	9	a centre of excellence, and this requires a team of
10	particularly encapsulated in what Ms Francis and I wrote	10	doctors, nurses and allied professionals. Unhappily,
11	at paragraph 262. I say no more than that.	11	peer review undertaken by the Organisation has
12	Haemophilia Centres I think my learned friend	12	
		13	identified persistent problems securing a full
13	Ms Gollop adopted that earlier, but it's if I		complement of multi-disciplinary team members.
14	I can take it in more detail if you wish SIR BRIAN LANGSTAFF: No, I've read it more than once.	14	I can just add at this point, we've seen what one of
15	MR KENNEDY: Then I wouldn't make you read it again.	15	the, I think unrepresented , Core Participant s Elisabeth
16		16	Buggins says about multi-disciplinary teamwork
17	Then just if I may, Haemophilia Centres are centres	17	I don't know if she's here today, but we agree
18	of excellence. We support the suggestions made by other	18	wholeheartedly with what she says.
19	Core Participants that Haemophilia Centres should be	19	The problems, and some of the solutions , we are
20	centres of excellence. It will come as no surprise, as	20	highlighting in paragraph 266 . In summary,
21	we say in our written submissions , that the central	21	commissioning must be cohesive and standardised across
22	issue is one of funding. Both , as we put it, adequacy	22	the UK. There must be a single service specification
23	generally, and consistency and transparency.	23	for all of the UK to ensure that all people with
24	We note at paragraph 265 that collaboration between	24	bleeding disorders have access to high quality and
25	UKHCDO and the Haemophilia Society and the Commercial	25	comprehensive care. And thirdly, any update of the
	117		118
1	service specification must be taken with the involvement	1	of illustration, UKHCDO been within the Department tent,
2	of all stakeholders, with particular focus on those with	2	if I can put it like that, in 1996 and 1997, it would
3	bleeding disorders so that their views are not just	3	not have been able to speak in the terms in which it did
4	heard but actively addressed.	4	when issuing guidance about recombinant products
5	Sir, we set out at 267 a form of words which may or	5	that's WITN3289048 nor in the terms in which it did
6	may not find favour.	6	about plasma collection from UK donors at the time of
7	Then, if I may, just turning to what I've described	7	variant CJD that's WITN7034006.
8	as the future of UKHCDO and the National Haemophilia		SIR BRIAN LANGSTAFF: Just give me that number again.
9	Database.		MR KENNEDY: Sorry, forgive me, WITN7034006. That is
10	Just referencing what I said a moment ago about	10	Professor Ludlam's letter to The Lancet of December
11	service standards, we would anticipate that the UKHCDO	11	
	•	12	1997, where he made two points : (1) what one might refer
12	will, as it has done in the past, and in conjunction		to colloquially as Recombinant for All ; and (2) to be wary of UK donors, given what was known about variant
13	with other patient organisations, play a significant	13	•
14	role in any future discussion about service	14	CJD.
15	specification.	15	We would therefore suggest that a recommendation
16	We suggest that its ability to play that significant	16	that had the impact of reducing or removing the
17	role reflects its position , or the position that it	17	independence of an organisation such as UKHCDO , and
18	occupies, standing between the patient and the	18	arguably would be carried over to any professional
19	Department, and it permits the Organisation to advocate	19	society that one might name, would be a significant
20	for patients to commissioners and to the Department, and	20	retrograde step. We note in this respect, sir, and are
21	it's for that reason that we would resist any suggestion	21	grateful for, the support that the Organisation receives
22	that the organisation go into a form of public	22	from the Scottish territorial health boards.
23	ownership.	23	At paragraph 220 of their submissions , they say
24	I said earlier that I mentioned three points about	24	this:
25	independence. I'll just say briefly this: had, by way	25	"The UKHCDO and the British Society for Haematology
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Organisation will keep you updated if you wish as to its

progress, but we cannot say anything more at this stage

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currently provide guidance on optimal treatment for 1 data selection but we do recognise what Professor Bird 2 people with bleeding disorders. Those organisations and said towards the conclusion of the evidence of the 3 the National Haemophilia Database also raise awareness statistics group and we would endorse what she says of developments in patient safety concerns. This work 4 about funding and about the need for greater is of great value in terms of both keeping clinicians up 5 epidemiological input. I just say this of the database: I said earlier that to date on best practice and enabling rapid identification of new safety concerns." 7 we think it's a -- that -- the first comprehensive They give a recommendation about security of database to be established in the world. It's a model funding. 9 that has been adopted elsewhere. It is a tribute to the On the issue of the future of the database, just 10 foresight of clinicians such as Dr Biggs that it exists briefly this, sir: we believe that it is uncontroversial 11 at all. It is a tribute to those in the 1970s and 1980s 12 that a database should be maintained to track disease 12 who encouraged and cajoled sometimes reluctant or 13 incidence, prevalence, trends and clinical outcomes and. 13 recalcitrant centres to submit their data. Without in particular, mortality over time. 14 their work, the database might have withered and ceased 15 As I said earlier, that permits identification of 15 to exist, as, sir, you know happened in Canada 16 16 unmet needs in the context of an evolving therapeutic I acknowledge that those people I have just referred and organisational landscape, and it informs healthcare 17 to are people who may elsewhere be criticised. 18 planning. It is also consistent with the Our simple concern, or rather the Organisation's recommendations for the European Association of 19 simple concern, is that a proposal -- accepting 20 Haemophilia, as I mention in my written closing. 20 a proposal of incorporating the database within the 21 wider NHS would expose it to the budgetary constraints I've addressed you already on what we say is 22 demonstrably the value of the database of the exercise 22 that we hear and read about every day. It would render 23 23 that the statistics group had to undertake. We don't it vulnerable to compromise due to decisions about 24 detect within the statistic s group, report or the oral 24 spending priorities . And we would suggest that there evidence, a particular concern about shortcomings of 25 must be significant doubt that had the database been 121 under NHS management for the entire period or for much 1 than we have said in writing . of the period with which you are enquiring, then you may 2 Sir, can I just conclude with this on behalf of well not have had access to the same extent of 3 UKHCDO. I say this to Lee's family, to Andrew, who longitudinal data that you have received. 4 spoke on Tuesday, who is determined that something That said, we acknowledge that the database must 5 positive should come from his experience . I say it to adapt and change to meet future needs. There must be 6 Barbara, who spoke most movingly yesterday , to those who continued involvement of those with bleeding disorders will speak after me from this lectern in the coming days on the management group. And again, we've touched on 8 and to the many, many more people who have given 9 evidence before you, sir, whether on paper or in person. that in writing. 10 I just add one final point, which is perhaps 10 We, on behalf of UKHCDO, hope that Sir Brian's relevant to ownership. Under the stewardship of UKHCDO, 11 report provides you with the answers that you have 12 the database provides UKHCDO with access to the 12 campaigned for and that you deserve . information from which it can generate treatment Sir, thank you. That is all I have to say on behalf 13 14 quidance. If they were divorced one from the other, 14 SIR BRIAN LANGSTAFF: Thank you very much, Mr Kennedy . The 15 it's unclear to us how the data would be accessed or 15 16 whether the Organisation would end up paying the 16 Inquiry recognises and thanks the UKHCDO for the data it 17 database for the data. 17 has supplied to our statistical experts enabling the 18 My last matter in terms of peer review is just this, 18 Inquiry to produce the degree of statistical certainty 19 sir: you well have seen that WMQRS, West Midlands 19 that is available. Quality Research (sic) Service I think, ceased to exist 20 Thank you very much. during the Covid pandemic. And the Organisation is 21 MR KENNEDY: Thank you, sir. 22 seeking to put in place arrangements for peer review or 22 MS RICHARDS: Sir, tomorrow, then, we have in the morning at 23 23 audit for the forthcoming round. I am sure that the 10.00 Ms Monaghan, on behalf of the Core Participants

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represented by Saunders Solicitors, and then at

have Ms Maharaj, who is the vice chair of the UK

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