Thursday, 19 January 2023

(10.00 am)

SIR BRIAN LANGSTAFF: Yes, Ms Gollop.

Closing Statement by MS GOLLOP KC

On behalf of 20 individual Core Participants and The Haemophilia Society

MS GOLLOP: Good morning, sir. Good morning, everybody.

These are the submissions on behalf of The Haemophilia Society. They are also submissions of a number of people with Core Participant status, represented by my solicitors, Eversheds Sutherland.

They include Elisabeth and Jonathan Buggins, and some of you may remember listening to Elisabeth, who was on a panel of parents with infected children; Sharon Lewis, ^name who is the widow of John Prothero, a member of the Executive Committee in the 1980s; Andrew Martin, ^name Paul Sartain, and David Watters, whose evidence many of you will also remember, he was the general secretary of the Society also in the 1980s.

I also represent 14 other individuals who would prefer not to be named. I am going to say a brief something about those, some who do wish to be named, just so you understand where they're coming from.

Elisabeth Buggins, the mother of four children, one of them Jonathan, three sons and a daughter. Her three

sons were all diagnosed with severe haemophilia A in the late 1970s and early 1980s and their care took place at Birmingham Children's Hospital under, then, Dr Frank Hill.

Elisabeth discovered that two of her three sons, Richard and Jonathan, were infected with HIV when she saw a list of names on the hospital fridge. As she says in her statement:

"Dr Hill was concerned that our knowing of a positive diagnosis would change our relationship with our child. There was no treatment and nothing could be done about the results. That was the attitude."

Her son Richard died in 1986 at the age of eight and she gave evidence in October last year on the panel that I just mentioned.

Her son Jonathan has made a statement to the Inquiry, not yet disclosed. His elder brother was Richard, the one who died in 1986, and Jonathan's statement addresses the impact of his treatment at the Birmingham Children's Hospital and of being infected. When he was 12, his parents brought a medical negligence compensation claim on his behalf which was settled at trial shortly before Dr Hill was due to give evidence, when Dr Hill's employer offered £75,000, which sum was accepted. And in his statement, Jon gives important

views on litigation: how he feels it does not improve patient safety and it enables organisations and individuals to hide, escape their responsibility, and obstruct the search for the truth.

Sharon Lewis, John Prothero's widow, has made a statement which has also not yet been disclosed. When it is, I very much recommend reading it. It's WITN3107001.

John Prothero, her husband, died from the consequences of an HIV-related infection on 19 October 1989, when he was 45 years old. He was the Society's treasurer and a board member, and she says in her statement that, during the course of John's life, he campaigned for the interests of people with haemophilia to be advanced in terms of achieving access to justice, acknowledgement of their situation, and also recompense in relation to the consequences that had befallen the haemophilia community.

Andrew Martin has made a statement which is disclosed and not quite yet on the website. He has haemophilia A. He was diagnosed with hepatitis C at some point in or around 1993. And he says:

"When I was diagnosed with hepatitis C, my mother was very quick to say that it was her belief that no doctor would ever do anything that would be detrimental

to my health, and it has been a shock to discover that we were not being protected or at least provided with the information that the Government or clinicians knew."

Paul Sartain has made a statement which is available on the website. He was diagnosed with severe haemophilia A in 1970 and affected with hepatitis B and C. And he says:

"In my view, my parents and/or I did not think to ask about risks because my treatment, cryoprecipitate or Factor VIII, was to ease the pain and suffering from a bleed. Many times as a young child I would have countless nights of disturbed sleep, pray for the pain to go away, and/or violently shake my head until I was so dizzy and feeling nauseous that I'd slump back on to my bed in a state of stupor."

And lastly, something about David Watters. He was the coordinator and general secretary between 1981 and 1994. He has made a statement, which is available, and he gave evidence on 10, 11 and 12 February 2021. David says his heart aches for victims of infected blood and he said:

"[He] won't ever forget the good friends on the Executive Committee and throughout the Society who I lost through HIV and AIDS and who I remember with affection."

The Society asks the Inquiry to find that it and its members were fortunate to have the services of Mr Watters. Prior to joining the Society he was a social worker and he worked particularly with homeless people. And after leaving the Society, which he did not want to do, he worked for another healthcare-related charity. His motivation throughout his professional life was to improve the lives of others less fortunate than himself, and he worked tirelessly in pursuit of that goal. He advocated for people with haemophilia at benefit tribunals. He campaigned for financial relief for those infected with HIV. He was there at the start of the campaigns for hepatitis C compensation. And he was a gifted administrator. He and the Reverend Tanner were patently good men doing the best they could for the entire bleeding disorder community in close to impossible circumstances. And you will all know that the Reverend Tanner's son Mark died of infected blood related illnesses and was ill throughout much of the time that the Reverend Tanner was chair of the Society.

Those are the pen portraits. I now want to quote from two reports. The first quotation is the same one that Mr Snowden gave you on Tuesday from the Bishop Jones' November 2017 report on Hillsborough. That was the crush at a football stadium in April 1989

which caused almost 100 deaths. Mr Snowden quoted that part of the report where the Bishop explained how he came by the phrase "the patronising disposition of unaccountable power" and talked about the experience of the Hillsborough families when, in all innocence and with a good conscience, they asked questions of those in authority on behalf of those they loved, and found the institutions closing ranks.

He went on to say this:

"And so the Hillsborough families' struggle to gain justice for the 96 has a vicarious quality to it so that whatever they can achieve in calling to account those in authority is of value to the whole nation."

"The concerns that it deals with are both historic and contemporary."

That applies just as much to all of you. Everything that you've done has had the same vicarious quality to it, and everything that you have done will be of benefit to the nation. The concerns of this Inquiry go further back even than the events of Hillsborough, and as yesterday's submissions on behalf of the DHSC, to which I'll return in a moment, amply demonstrate, they are not only contemporary, but pressing.

The second quotation is from Baroness Cumberlege's report *First Do No Harm*, and that was published midway

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

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

"We have found that the healthcare system in which I include the NHS, private providers, the regulators, and professional bodies, pharmaceutical and device manufacturers and policy makers, is disjointed, siloed, unresponsive and defensive. It doesn't adequately recognise that patients are its *raison d'etre*. It's failed to listen to their concerns and when belatedly it's decided to act it has too often moved glacially. Indeed, over these two years we have found ourselves in the position of recommending, encouraging and urging the system to take action that should have been taken long ago. The system is not good enough at spotting trends in practice and outcomes that give rise to safety concerns. Listening to patients is pivotal to that."

It all sounds horribly familiar. *First Do No Harm* is a document which I will come back to, if I have time,

so I'd like to put it on screen so that those of you who are understandably not familiar with it can see the similarities here.

Thank you, Lawrence. You're ahead of me, which is great. Page -- we've got paragraphs 1.1 to 1.3 and those are on internal page 0009. That looks like 18. That's it.

It's really close type. I don't know if we can enlarge 1.2. Very briefly, so that it makes sense, this is what she was looking at: hormone pregnancy tests, which were taken off the market in the late 1970s, thought to be associated with birth defects and miscarriages; sodium valproate, which is an anti-epileptic, which causes physical malformations, autism and development delay in children when taken by their mothers in pregnancy; and pelvic mesh implants used in the surgical repair of organ prolapse and to manage urinary incontinence, linked to crippling, life-changing complications.

If we look at page 0011, she identified right at the bottom 16 common and compelling themes which chime very much with your experiences. Number 1:

"the lack of information to make informed choices ..."

Then over the page.

"Lack of awareness of who to complain to and how to report adverse events;

"the struggle to be heard;

"not being believed;

"dismissive and unhelpful attitudes on the part of some clinicians;

"a sense of abandonment;

"life-changing consequences, not only for those directly affected, but for their families and friends too;

"breakdown of family life;

"loss of jobs, financial support and sometimes housing;

"loss of identity and self-worth;

"a persistent feeling of guilt;

"children becoming their mothers' and siblings' carers ..."

We might say fathers', husbands', brothers':

"clinicians untutored in the skills they need to make a proper diagnosis;

"clinicians not knowing how to learn from parents;

"inaccurate or altered patient records;

"a lack of interest in, and an inability to deliver the monitoring of adverse outcomes and long-term follow-up across the healthcare system."

All of that will be horribly familiar to all of you.

Thank you, Lawrence. You can take that down.

To that list, I would add two things. The first and lesser is the indignity, harshness and hostile nature of the so-called support schemes. The other more important matter is death and bereavement. There are no words that can truly capture the depth and intensity of suffering that you have recounted to us. Some witnesses may have found making statements or giving oral evidence cathartic but, for others, it's been traumatic. They've been through so much, and everybody at the Society is humbled and deeply grateful to them for suffering further through telling us about it.

Doctors really struggle to talk to patients about risk in a way that gives patients the information that they need and enables everyone to make the choice that is right for them as an individual.

Informed choice is the heart of what went wrong over and over again. Safe treatment was taken away by the Government so that it was not an available choice, or doctors consciously or unconsciously took that choice away because they acted without thinking or thought they knew best. There can be no more compelling teaching tool than the firsthand accounts of what infected blood has done to you and that you have provided to us

selflessly by giving us the evidence that you have done, and allowing it to be captured on camera. Thank you.

Thank you too to the Inquiry. The kindness, calm, and consistency of the front-of-house staff, their regular meetings around the country, the absolute professionalism of the legal team, we know this more than you do because we lawyers watch other lawyers, but it really has been the best of the best -- and the technical teams.

Sir Brian, your attention to detail and your very personal involvement have been notable features every single day of this long-running Inquiry. If the culture that your vision for your Inquiry has created could be exported into the NHS and Government more widely, that would be grounds for hope for a state that is more listening, compassionate and responsive to the needs of those it here to serve.

Which brings me to yesterday. We're all familiar with the phrase "actions speak louder than words". Yesterday we got no actions and no words. But, more precisely, we got a lot of words that said nothing at all. The first thing to say is that none of that is the fault of Ms Grey, King's Counsel, or her team. I have no reason to doubt, and I think you should not either, that she and her team have worked hard and to a very

high standard to further the work of the Inquiry and provide statements and submissions that, so far as can be seen from the outside, are clear, thorough and meticulously searched and referenced.

Ms Grey said as little as she did because her client, the Department of Health and Social Care, provided her with nothing more that she could say. The fault and the responsibility lies not just with the Department she represented but the whole of the Cabinet, from the Prime Minister down.

When we were informed at the end of the day on Tuesday that the Department's submissions would not start at 10.00 as timetabled but instead at 2.00, and be over by 3.00, there were a lot of questions about what that might mean. There was, within the Society, a degree of expectation that the submissions were going to be short because the Government had something of substance to announce. Instead, time that could have been put to good use by infected and affected Core Participants was wasted.

In September 2018 Ms Grey informed the Inquiry that the Department accepted that things happened that should not have happened and that it was sorry. Yesterday, she delivered the astonishing news that after a four-year opportunity to reflect on those things that should not have happened, the Department had somehow gone backwards and is now unable to identify what it was sorry for when the Inquiry started. There's been some sort of groupthink amnesia.

Ms Grey referred to the fact that on 15 December, the Cabinet Secretary told the House of Commons that the Government accepted moral responsibility for infected blood but, yesterday, it was unable to say through its lawyers why it has accepted moral responsibility or what that actually means.

My clients accept that they cannot force the Department to say what it is sorry for. Sir Brian had a go, and if he can't make that happen then neither can we. But the cowardly approach taken by the Department has three consequences: first, what little trust there might have been has gone.

Second, and this was not the Society's position before yesterday afternoon, it now joins with the submissions of Mr Snowden, King's Counsel, on behalf of those represented by Collins, that there need to be further interim recommendations on compensation for parents, children and grandchildren who have been bereaved by infected blood. The payments of £100,000 were only paid because, Sir Brian, you made an interim recommendation in that regard. Bereaved people have had

nothing and they deserve something now. There is no reason to believe that the Government will do anything without a recommendation from you.

Third, it is absolutely imperative now that this Inquiry does not end with the publication of the report. For as long as your Inquiry is alive, Sir Brian, people have trust and hope that there will be accountability, compensation and lasting change. The fear is that, as soon as you close this Inquiry, there may be delay, backsliding and nothing will really change. We would not want see your report to be as widely disregarded as it would appear Bishop Jones' report into Hillsborough has been.

Yesterday rather proved that that fear may well be well founded. A way must be found to hold the Government's feet to the fire after the report is published.

Ms Grey mentioned Mr Quin's statement in the House of Commons on 15 December. We would mention the debate in the House of Lords on 20 December last year, five days later. I've given the reference to Ms Richards, and we'll make that reference available to you, Sir Brian.

There is a transcript of the debate on the TheyWorkForYou.com website, which you may be interested

to read. Baroness Neville-Rolfe, who is the Minister for the Government in the House of Lords, said that Ms Sue Gray, at the Cabinet Office, is bringing together permanent secretaries from the Treasury, HMRC, the Cabinet Office, DHSC, the DWP, the DLUHC, (I think that's the levelling up one), the Devolved Nations and others. She told the House of Lords that this group met monthly and that -- this is a quote:

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

She then said that careful consideration was being given as to whether there should be an arm's length body. She said the Government would want to work with "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 a Parliamentary question, Mr Quin said that the cross-Government working party was taking forward work on the establishment of an arm's length body.

The Society makes three points. The first is about

the need for the working group to listen to infected and affected people's views on the compensation framework they want and need now, not when the finished product is delivered.

Returning briefly to the Government's implementation of the Cumberlege Review's recommendations, the Society notes -- and it's one of my New Year's resolutions to stop bombarding Ms Richards with emails telling her to listen to Woman's Hour -- that she gave an interview to the BBC -- there was an interview on Woman's Hour on 3 January 2023, given by the Patient Safety Commissioner. That was a recommendation of Baroness Cumberledge's report and Dr Henrietta Hughes has been in post for some months now.

Dr Hughes talked about the mesh removal centres which have been set up in response to the Cumberlege Review's findings and Dr Hughes told the BBC that these centres are not meeting the needs of users because when the clinics and systems were designed, the views of the women harmed by mesh were not listened to. The Society 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.

Second, transparency. The Society would suggest -- and, Sir Brian, we might like to tempt you into considering an interim recommendation -- that it is reasonable to ask that we have published (i) the names 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 bite 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 behind me who could probably give you the list of people to contact right here and right now. You really don't need to ask members of the House of Lords to do your publicity work for you. It's all here, handed on a plate, if you would only like to come and listen.

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 achieved 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?

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

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 prepared 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 1985 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 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 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

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 1977, 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

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 taxpayers, 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.

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.

Concentrate allowed you to live your life to the full. What home treatment took away, and it's probably not possible for those of us who don't have a bleeding disorder to understand this, was the pain of an untreated bleed, the fear of pain, and the spectre of bleed-induced permanent disability.

In January 1972, the Society republished an editorial from The Practitioner, a journal which is primarily aimed at GPs -- which tells you something about how widespread was the state of knowledge at that time -- and the editorial talked the reader through the work of J Garrott Allen in 1970 which identified the fact that commercial blood is riskier than voluntary blood. And the piece in The Bulletin explained why: paid blood came from prisoners, people on skid row, people addicted to drugs and alcohol.

So the Society knew that in 1972, before the first US products were licensed in 1973, and it made that knowledge available to anyone who read The Bulletin.

At the time, the NHS wasn't producing enough cryoprecipitate or concentrate to meet the needs of patients, and that was a concern to the Society. The Society didn't particularly mind what form the treatment took so long as there was enough of it to go round, and it did whatever it could to plug gaps in the NHS

provision. There's a report in a 1974 Bulletin of the Society offering a hospital assistance with volunteer workers to help increase production of cryo, and the response from the hospital was that that help might be resented by technical staff and could result in industrial action.

If you read The Bulletins of the time, there are a host of examples, and we've given them in our written submissions, of what the Society was doing to try to make treatment available to people across the country, providing home freezers and all sorts of things like that.

In 1974, Dr Biggs published a letter in The Lancet saying that there was a shortage of treatment and that 90 per cent of UK patients were getting less than the optimum treatment for their complaint. Non-urgent operations were being cancelled and there was a delay in putting patients on home treatment.

In that context, the Society supported an increase in the supply of concentrate, but there's no evidence that it campaigned for licences to be issued so that blood products could be imported from America. The minutes of the meetings of the Centre Directors in October '72 and January '74 record that it was the Centre Directors who were pressing for permission to do

that and that, given the choice, none of the Centre Directors preferred to use cryoprecipitate; they all preferred to use concentrate Factor VIII.

It was David Owen who was the Health Minister when American blood products were licensed for use in the NHS in '73. As he explains in his witness statement, he knew what he was doing. He had reviewed Titmuss' book for the New Statesman in 1971 and he identified in his review the fact that there was no moral, financial or administrative case for using US products in the NHS. He knew the risks to the bleeding disorder community that he was sanctioning. This was a stopgap measure. And when he made it possible for US blood products to come into the country in '73, he committed the Government to self-sufficiency by 1977.

That was the aim. The problem was that the aim wasn't achieved, and there was never a plan B. The Society was concerned at the time that that date was going to be missed. It spoke to Dr Owen at the end of 1975, talked to him about what could be done, about plasmapheresis, the regional structure of BTS and other matters, and repeatedly expressed its concern about increasing reliance on US commercial concentrates, but nothing changed.

In his letter to the Archer Inquiry in August 2007,

Chris James, the Society's chief executive at the time, summarised the efforts that the UKHCDO went to in 1977, '78, and 1980. That's ARCH0001014.

So in all of those years, the UKHCDO was trying to impress on Government that it needed to hurry up with self-sufficiency with the same lack of success. So in the early '70s there might have been some knowledge amongst some members of the bleeding disorder community that large pool concentrates had an increased hepatitis risk and that US products were worse than NHS ones, but what you know and what you really get and understand are two different things.

And the World in Action documentaries were eye opening. So this is a good point to replay part of the second documentary broadcast in December 1975, where patients, parents and the Society's Executive Committee were asked for their reactions to the first broadcast, which showed how blood was collected in the US on skid row and the added risks of products.

Take it away, please, Lawrence.

(Video played)

MS GOLLOP: Sir, I see the time and I'm told that cometh the time, cometh the Paddington hard stares from the bench. So I don't know if this is marmalade sandwich time or not?

SIR BRIAN LANGSTAFF: Well, I think it might be a bit early, if there are, let's say, a few more minutes that you can take us up to, say 11.15.

MS GOLLOP: Yes, with pleasure.

Well, that was December 1975. Probably, one imagines, filmed not long before the Society had its meeting with David Owen and talked to him about plasmapheresis and other things that could speed up production in this country.

I want to fast forward, if you'll come with me, to 1983, and the Society's May advice. Despite its contacts with civil servants and the doctors on its Medical Advisory Panel, when it came to the two infections that destroyed so many lives, including the lives of those who you've just seen talking, the Society had just as few facts and as little reliable information about risk as any patient with haemophilia.

The Inquiry has produced an impeccable chronology of the knowledge of risk. When it comes to what the Society knew, it's as important to look at what it didn't know but could have been told, as to what it did know. The Society trusted people with knowledge in the NHS and in the Civil Service to share what they knew in the way that the Society shared what it knew with those people. But this was not an information two-way street.

In January 1983, Professor Bloom attended a Hepatitis Working Party meeting where Dr Craske talked about the information he had had from the CDC in America. At that time, there were ten cases of AIDS in haemophilia A patients in the States, and it seemed to the CDC possible that Factor VIII or other blood products might be implicated. That was in January.

On 7 March 1983 Dr Evatt at the CDC in the States wrote to Professor Bloom and he said this -- "As you can imagine" -- I think you have to try to imagine an American accent, which I won't do, but, you know, take yourself back to Atlanta:

"... AIDS is having a major impact on the treatment of haemophiliacs here presently. The evolution of the epidemic is occurring with a frightening pace. We presently have 13 confirmed haemophiliac patients with AIDS in the United States. One of the patients has a Factor IX deficiency, one is bisexual. In addition, five more highly suspect cases are under investigation. The incidence rate has been increasing in haemophiliacs and the epidemic curve parlays that of the total epidemic curve. The first case appeared in a haemophiliac in January 1982, a total of nine were reported by December. Of those, eight died in 1982. I suspect it's a matter of time before you begin to see

cases in the United Kingdom."

It is truly shocking to read that letter alongside Professor Bloom's advice to the Society and its members two months later. It's clear from all of his actions that Dr Evatt wanted the facts about AIDS and the threat of AIDS to people with haemophilia to be widely known. He was doing everything he could to get the word out. This was not, in any sense, a confidential letter. Professor Bloom could and should have shared it with the Society.

As Mr Snowden pointed out on Tuesday, ten days after the date of that letter, on 17 March 1983, Professor Bloom diagnosed AIDS in his own patient with haemophilia, Kevin Slater, and it was less than two months later that he gave advice to the Society and its members that:

"The cause of AIDS is quite unknown and it has not been proven to result from transmission of a specific infected agent in blood products. The number of cases reported in American haemophiliacs is small, and in spite of inaccurate statements in the press, we are unaware of any proven case in our own haemophilic population."

The Society will never know why Professor Bloom did not share with it the letter he received from Dr Evatt

in March, with its devastating and accurate warning that the epidemic of AIDS amongst people with haemophilia in the US was likely to cross the Atlantic and arrive in the UK. It will never know why he chose consistently to minimise the risk of AIDS. Before this Inquiry, the Society did not know the extent of his breach of the Trust it put in him, and the distress has been considerable. The Society trusted the doctors providing it with advice to inform them of the facts and not withhold them even if the facts were difficult to hear. It particularly trusted Professor Bloom, who was not only the UKHCDO chair, but a trusted adviser to Government at a high level.

He abused the Society's trust.

Other doctors have told the Inquiry that there was a lot of confusion. There were lots of conflicting theories. Things that now seemed clear were not clear then. But facts are facts and Dr Craske and Professor Bloom had the facts about what was happening in the States and the CDC's working approach to a likely epidemic. As you said, Sir Brian, during the presentation on knowledge of risk, the numbers were going up. The Society and people with haemophilia were entitled to know what the numbers were.

As a follow-up to its "Killer Blood" article in the first weekend in May 1983, The Mail on Sunday published a further article called "Action to Ban Danger Blood", and that reported a Dr Pinching as saying that, and I quote:

"I wouldn't dream of giving a patient American blood products. We have to find an alternative immediately."

It seems likely, and we invite you to find, sir, that it was because of that quote in the national press that the Society either invited Dr Pinching to write for The Bulletin or he said to the Society he would like to write something for them.

Dr Pinching did not treat people with haemophilia and he wasn't a Centre Director. He was outside the mainstream and, if there was an alternative to the Bloom view, it was clear from what he had been reported as having told The Mail on Sunday that he would be a good person to provide that counterblast. He did write for the bulletin and the article he wrote was rather more cautious in tone and more informative than what Professor Bloom had had to say.

Lawrence it's PRSE0000411 at page 11. It's squidgy writing but hopefully we can make it a bit larger.

This is his piece in The Bulletin and, if you look on the right-hand column, he tells you really quite a lot:

"The pattern of the epidemic has suggested that AIDS may be due to an infectious agent transmitted by intimate contact ..."

So you've got a reference to sex there.

"... or blood product inoculation, in a way reminiscent of hepatitis B virus. While there are many other suggested causes, this one currently seems the most likely. The agent is probably a virus but it has not been identified, so no tests. A particular problem is that there appears to be quite a long period (months or years) between the exposure to the causative agent and the person becoming ill, during which time he or she may be infectious."

Then in the second paragraph, starting "Over 2,000 cases", about four lines down:

"... the disease carries a high mortality."

Then if you jump a bit further, five or so lines down:

"The syndrome is rightly being viewed with some concern. In the present state of knowledge, a major objective must be to try to reduce the risk of transmitting the disease further.

"How does this affect haemophiliacs?"

He said:

"AIDS has affected 1 in 1,000 in the USA and two

patients in the UK."

So you're getting that information.

"The immediate source of infection in such patients is thought to have been Factor VIII concentrate, derived, as it is, from thousands of donors."

So you're getting the information about where it's coming from and the fact that this is large pool concentrate, very different to cryo.

"On the other hand, this new and to some extent theoretical hazard of using concentrates has to be set against the enormous benefits, especially for home therapy. As in any other medical setting the risk has to be balanced against the dangers of the disease itself. Factor VIII concentrate from the USA may be the most likely to contain the AIDS agent. However, the risk is probably small and no source can be regarded as completely free from risk. Furthermore, the USA is the only country capable of providing the quantity of Factor VIII currently needed by UK haemophiliacs."

Then a few lines down:

"The present balance of opinion among Haemophilia Centre Directors in the UK therefore is that imported Factor VIII concentrate should continue to be used for those selected patients already receiving it."

He sets out who those are. Then he sets out those

who shouldn't get it: children, those with mild disease. And he says the source of Factor VIII concentrates will need to be kept under constant review, as will blood donor policy, both by the medical profession and the relevant industrial concerns, to minimise or eliminate the risk.

Now, two points to make. One, all of that was good, sound advice, with some facts, and the Society would have done well to keep repeating it.

Second, whatever it was that he did or did not say to the Mail on Sunday, by the time he was writing for The Bulletin in the middle of 1983, Dr Pinching was giving the same advice as Professor Bloom.

SIR BRIAN LANGSTAFF: Well, was he, or was he simply saying the present balance of opinion -- balance of opinion -- among Haemophilia Centre Directors -- he's not actually saying it's his opinion, is he?

MS GOLLOP: No, he's not, and one may think that he chooses his words rather carefully. The difficulty with the balance of opinion is that it wasn't a balance of opinion. It was the unanimous opinion.

SIR BRIAN LANGSTAFF: Well, at the executive level, certainly.

MS GOLLOP: But he says what he says.

SIR BRIAN LANGSTAFF: Yes.

MS GOLLOP: And he doesn't say --

SIR BRIAN LANGSTAFF: But he doesn't say what his view is, and that has to be balanced, when I come to look at this and think about it, with what is reported in The Mail on Sunday, and for that matter I recall, whether it was that or whether it was the Northern Echo or another paper, he was recorded saying it was madness to take a blood product from a country in the middle of an epidemic.

MS GOLLOP: Yes.

SIR BRIAN LANGSTAFF: Which would suggest his view, at least at that time, and for the purposes of that report, if properly reported, was that it shouldn't be admitted into the country. There we are.

MS GOLLOP: That's right.

And as I said, he is not a haematologist. I think he's an immunologist, so far as we know not patient facing. So he wasn't challenged with what to say to a patient and what to prescribe and that the shortages that there were. But the piece that he wrote is more nuanced and much more helpful than anything than emanated from Professor Bloom.

Looking abroad, the risk minimisation measures unanimously adopted by the World Federation of Hemophilia in July 1983 were very similar to the

UKHCDO's guidelines. Not a single doctor in the UK contacted the Society to voice any disagreement with the information it published about AIDS between 1983 and 1985, and many haematologists have given evidence to the Inquiry about the fact that they made The Bulletin available to patients. The Society's belief from '83 to '85 was that without US concentrates there was not enough blood product in the UK to treat patients, and that if left untreated, patients with severe conditions would suffer bleeds which would certainly cause damage to joints. That was the context in which, in September 1983, the Society urged the Government to continue to import from the US, which was something that the Civil Service had already decided to do in May '83 in any event.

In essence, the treatment advice from Centre Directors, supported by the Department of Health and all parts of the NHS system, did not change until heat-treated product was universally adopted in 1985.

Perhaps the best evidence of how the Society was thinking in this crucial period comes from John Prothero, who you heard at the end of that clip and who, I remind you, died in October 1989, and other people with haemophilia in the July 1985 documentary Bad Blood.

I'm going to play some clips in a moment and, to set the scene, by the time this programme went out we're a decade on from the one we've just looked at, and the programme started by saying that five people with haemophilia had died of AIDS in the UK. It discussed the numbers of people estimated to be infected in the UK, and we see Dr Peter Jones saying that, for those infected, there's a 90-95 per cent chance that they're going to be all right, and Dr Savidge saying that the risk of infecting a partner is about 5 per cent.

So we will play some of those clips now, and they end with John Prothero.

Thank you, Lawrence.

(Video played)

MS GOLLOP: There may be some Core Participants who have a feeling that the Society should have done more to campaign on behalf of people who were infected with HIV in the later 1980s, I don't know. For those who do have that feeling, I would strongly recommend that they read the statement of Sharon Lewis, Mr Prothero's widow. It talks movingly about his decision to do as much media work as he could between 1985 and when he died in 1989.

He felt that it was incumbent on him to be open about his infection to combat the stigma of AIDS and to explain the predicament of people who shared his

situation, and he worked hard to achieve acceptance by the Government of its moral responsibility towards people infected by contaminated blood, and he fought for justice and financial redress for them in the few years left to him between speaking to you then and his death.

Sir --

SIR BRIAN LANGSTAFF: That's plainly a convenient moment. So we'll take a break, and we'll come back at 11.45. So 11.45.

(11.16 am)

(A short break)

(11.45 am)

SIR BRIAN LANGSTAFF: Yes?

MS GOLLOP: I'm going to make two points in relation to hepatitis NANB, as it then was. We've addressed this at some length in our written submissions, and I'm not going to say more than that about this issue now.

On Tuesday, Mr Snowden took you to Dr Walford's 1980 memo, where she captured the point, and her recently acquired knowledge, that 90 per cent of post-transfusion hepatitis was of the NANB variety and that it could be rapidly fatal. And, sir, you'll recall her evidence that she escalated a communication of that knowledge up the chain and sent her memo around the Department quite widely and to her superiors. So I won't take you back to that.

What I would ask us to do, just very briefly, is then fast forward about seven years to Dr Smithies' memo of 17 February 1987. That's DHSC0001383. This is a three-page document and this is the last page.

It's worth looking at in a little bit of detail. I think we've looked at the first paragraph more than once, but the second paragraph is of interest as well. She talks about the "finite number of haemophiliacs who have contracted HIV infection" -- and remember this is February 1987, so significant numbers of people are already, in the haemophilia community, dying of AIDS at this point in the UK -- and their position being "pitiful", and having "attracted great sympathy", in part because of the "perceived stigma".

It wasn't just perceived; it was objectively as well as subjectively present.

Then she says:

"The equally sad fact that a number of haemophiliacs will undoubtedly die of chronic hepatitis as a result of non-A non-B infection has not been recognised publicly."

Which suggests that it's been well known within the Department privately but somehow not recognised publicly. So that's of concern.

Then a passing interest, she says -- she makes --

draws a parallel with non-steroidal anti-inflammatory drugs, and some patients being relieved of pain by using those over-the-counter drugs. And she says:

"I find it difficult to advocate that there are any special circumstances surrounding the care of haemophilia which makes their case for compensation greater than that of other patients who take medicines which kill them. That is, of course, provided the doctors caring for the patients have prescribed their treatment in a proper manner."

A few points arise. Number one, the last sentence is a bit of a big "if" when it comes to infected blood.

The second is, it's a false equivalence between anti-inflammatory drugs, which one can choose a variety of painkillers and buy over-the-counter, and infected blood. It smacks of whataboutery. There are so many differences, it shouldn't be necessary to spell them out.

AIDS at this time had a very high mortality rate. Drugs that you can buy over the counter and take for arthritis if you choose do so really didn't. And it's a paragraph that seems lacking in compassion and lacking in a sense of the reality of people's lives in February 1987.

SIR BRIAN LANGSTAFF: An example of a non-steroidal

anti-inflammatory drug is something like ibuprofen. And to suggest -- you're saying, I think, are you -- that somebody who takes ibuprofen suffers stigma for instance, or anything equivalent, is not appropriate?

MS GOLLOP: Not very.

SIR BRIAN LANGSTAFF: No. Thank you.

MS GOLLOP: If we keep that in mind -- you can take it off the screen. Thank you, Lawrence.

If one goes forward eight months or so to 3 November 1987, that was the date when the then minister in the Department, Mr John Moore, had the memorable meeting with the Society -- and the DHSC in its written submissions has reproduced some of the evidence in that regard -- a memorable meeting with the Society at which he was reduced to tears. Because attending this meeting were three young men who were infected with HIV/AIDS who explained to him their fears for themselves and their families. And Mr Roger Moore, the civil servant, explained that he'd never seen somebody cry in a meeting before.

The Society would suggest that in a properly run health system that was not disjointed and siloed, the Minister, Mr Moore, would have been told in preparation for this meeting that infected blood had given people with haemophilia not just AIDS, but also hepatitis NANB,

which could also be fatal, and from which a number of them, in Dr Smithies' words earlier that year, were undoubtedly going to die.

Given Mr John Moore's reaction to what he heard in the meeting, it is reasonable to think that he would have acted on information about that second killer virus had he been told about it, as one might think he should have been.

The second point, if we fast forward almost a decade to the World in Action programmes, which were a valuable resource, broadcast in October 1996, with Lord Horam. That's HSOC0008602.

The interviews with him are interesting on a number of counts, not least he gives the line oft repeated by politicians since, "Well, we don't want to spend money on compensation, it would be much better if we used that money for the wider community", at the same time refusing to fund recombinant, so not using the money saved by not paying compensation for the benefit of the wider community.

But he's also asked about hepatitis C, as it was then called. It was put to him in October 1996 by the programme that £26 million had been spent on research on AIDS and just £1 million on researching -- this is what's put to him -- "the hepatitis epidemic which 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 facts 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 1996, 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

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, HSOC0003459, 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

moral not legal grounds, and that was an unusual tactic 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 £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".

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

After the award of the ex gratia payment, the number of claimants into the litigation increased because many people used all or some of their £20,000 payment to fund joining the litigation. So the Society launched another media offensive for out-of-court compensation, and it did so despite Dr Kernoff, who was sitting on its Medical Advisory Panel, advising the Society against becoming involved on the grounds that "People might start suggesting that people with haemophilia are too greedy". The reference for that is HSOC0010954.

As you know, settlement of the court action was reaching after Mr Justice Ognall's intervention in June 1990 where he repeatedly referred to a moral duty.

Much later, in June 2018 -- I think that must be 2008 -- Mr Graham Ross, the solicitor who acted for very many of the claimants, appeared before the Archer 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 litigation, and the Society notes the statement of Sir Rupert Jackson, who was then junior counsel for the claimants in the litigation. He says that the case was very worrying, that plaintiffs were dying every month, that by the time of the settlement 148 patients had died, and the case "faced significant difficulties on liability and causation".

He described the central defendants as "intransigent", and said in his view "It is unfortunate that the Government of the day did not face up to its moral responsibility in the same way that the present Government has", at which point, after yesterday, we might say "up to a point, Lord Cooper".

Turning to hepatitis C. The Society is painfully aware that there are a number of infected and affected people who feel that it did too little too late and it wasn't there for the community at a time of need. The Society has done its best to respond to those concerns in two very lengthy witness statements made by its current chief executive, Kate Burt. I think only one of them has just been made available.

As she says in those statements, the Society hears you, deeply regrets that you feel let down and would welcome the opportunity to listen to those who feel harmed. The mid-'90s were a time of crisis for the

charity. Those running it were exhausted by campaigning and the organisation was on the brink of bankruptcy. Some of the trustees felt that the Society wasn't representing them and they'd achieve more from the outside than they could from the inside and they set up their own campaigns.

The documents referred to by Ms Burt show that there was a considerable amount of working together, but there's no doubt that these splits were painful and sad. Everybody wanted the same thing, but it may be that the combined effect of different tactics taken by different campaigners was greater than one single campaign would have been. The Society felt it had a responsibility to the whole of the bleeding disorder community, and one can see that in its attempts to meet everyone's needs, thereby perhaps pleasing nobody and dissatisfying a cross-section of the membership.

If we look briefly at a page from the 1998 Bulletin, WITN6392059 at page 10.

Squidgy print, which I hope you can read.

This is a letters page.

Lawrence, I don't know if you can just put the whole page on so that people can see what it -- there, it looks like that.

It's printing three letters which are a response to

the chair of the Hampshire Group. If we look at the top left, this is from Stan Cockburn, the chair of the Manor House Group. And the writer of the article that these letters are responding to is Mary Clarke. And he says:

"She is concerned that the Society will divide into different groups. I must ask, is she living in the clouds? The Society is already split into several groups: we have haemophiliacs who have received a very derisory payment for being infected with HIV. We have young people who will be receiving recombinant products now coming on line, as they should. What have the people of my own generation been given? Absolutely nothing."

And in the last paragraph of that letter:

"... [the] Editorial stated that the HCV campaign has highlighted the need for better treatment for hepatitis patients. This lesson should have been learnt from the HIV campaign and not as an afterthought."

The editor's reply is:

"We need to help everyone with haemophilia. All those I speak to agree that we must continue the HCV campaign and we shall. However, I would like to see all of us helping each other and not just following our own particular needs."

I think you can see how that is both a reasonable

response and, for those with particular needs and infections, an unreasonable one. It's the Society trying to please all of the people all of the time and failing to do so.

Then we've got another letter if we look at the bottom of the left-hand column:

"Wake up, Mrs Clarke. The haemophilia community has been divided ever since some people receive viral infections through their contaminated treatment. We shall continue to be divided until we can secure safe treatment for all and until there is some recognition by the Government that they have a moral obligation to us."

Then at the end of this letter:

"There have been far too many mistakes made at the expense of haemophiliacs and we need to shout about it."

I'll say some more about the Society's campaigning tone in a moment.

And lastly, you get a letter from a different perspective.

"I have been married for 30 years to a man with haemophilia. [He] is now 63 and one of the few haemophiliacs who did not contract HIV. He has now been told he is [hepatitis C] positive ... I feel this letter from Mary Clarke points to the fact that people like [him] have been forgotten. We feel guilty that he ONLY suffers so far from bleeds."

And in the last paragraph:

"There must be many other haemophiliacs like *(redacted)*, who feel they cannot approach the Society because they only have haemophilia."

Thank you, Lawrence.

SIR BRIAN LANGSTAFF: Just one moment. I wonder if we can redact the name there.

Thank you.

MS GOLLOP: The fact that people felt they had to leave the Society remains a source of great regret to the charity now. This hurt, and everyone involved in these splits was hurt, were a consequence of Government forcing physically injured and psychologically damaged and bereaved people to fight for justice and compensation, and it is partly these experiences in the 1990s that causes the Society to now advocate strongly for a system based on swift and fair redress for NHS patients who suffer avoidable harm from a system's breakdown.

Lastly, something about saying it right.

The Society recognises that there are some people who feel that it hasn't been vocal or hard hitting enough in speaking truth to power, and has, in summary, been too deferential. Its focus on achieving the greatest good for the greatest possible number has

caused it to take a pragmatic approach and to be an organisation, so far as it could, that Government could do business with, when it was possible to do business.

The brief account of the campaigning work that the Society did between 1987 and '91 to obtain some financial redress for all people with haemophilia infected with HIV as soon as possible illustrates, we submit, how tenacious the Society was and how it didn't bow to pressure but kept on campaigning for more after the £20,000 lump sums were paid. And it was capable of hard-hitting tactics at times. For example, when campaigning for the out-of-court settlement in 1990 it ran an ad campaign. We've not been able to find a picture of this, but there is a description of it in the letter of complaint that was written about the ad campaign to, I think, the BMJ. And this is a new document that's been given the number HSOC0029910.

It had a picture of a child, and the caption read:

"Heredity gave him haemophilia, then the NHS gave him AIDS."

But there was a complaint about that, and I think, trying to piece it out, the essence of the complaint was that ad campaign ran in 1990 and people looking at it might think that the NHS was giving children AIDS in 1990 rather than in the 1980s. In any event, a Dr Bird

wrote a letter of complaint with, it seems, the knowledge of some members of the Civil Service, and a complaint was made and upheld to the advertising standards board.

All of that said, generally, the Society has had most campaigning success when appealing to the Government's moral, not legal duty. And the Carpet of Lilies campaign, which witnesses have said they found moving, relied on personal accounts of the damage done to individual lives when Government loses sight of its moral obligation to keep a section of the public safe, and that was a powerful campaign.

There is some evidence that a quiet explanation of a situation can be more effective than a loud one. Mr Roger Moore told the Inquiry on 18 January last year that when the Society delegation, which included the three young men with haemophilia infected with HIV came to ask the Minister for money, and that was a meeting that the Minister went into firmly decided that no money would be forthcoming, the public servants were expecting anger and a difficult meeting. Mr Roger Moore said, "And what struck us actually was that these were people who had a right to be angry, and they weren't. They were only concerned about the families that they'd leave behind, and we listened and we were really moved."

The Trust and schemes were never adequate, fair or dignified, but they were the best that the Society would achieve in the face of Government refusal to compensate people for their injuries. And the Society's efforts on behalf of the whole community meant that many people who would not otherwise have done so did at least get something in their lifetime, even though it was not enough.

That brings me to the present. And to an apology.

In 2017, the Society issued an apology as follows: for its statements during the 1980s, reassuring patients that new factor treatments were safe and to continue using them.

"We also lobbied the Government to continue allowing the import of products from the USA.

"The advice we gave our members was based on guidance from the Haemophilia Centre Directors (now known as the UKHCDO) and from the Government. The leadership and trustees of The Haemophilia Society were misled and, as a result, unwittingly further contributed to the Scandal.

"However, we accept that our actions and statements at the time, while well-intentioned and based on expert advice, have subsequently been shown to be damaging to the community and false. For this, we unreservedly apologise."

The submissions of some other infected and affected Core Participants make it clear that some people feel that does not go far enough.

Now, there's a risk that the Society will sound like the DHSC, and I hope you won't take what I'm now going to say in that same way. The point of the Inquiry for the Society is multiple, but one of the points is to listen to Sir Brian's objective and fully informed judgment, and that will be an important part of the learning it does about itself in the past and now.

The Society thinks that it makes sense to reflect on his findings before it says any more than it said in 2017. It will then have the benefit of something that is considered and not the Society marking its own homework, but listening to a proper examiner and a thoughtful dissection of what it got right and what it got wrong.

The Society said this in its written submissions: that it would like to say to the Inquiry and to each person infected and affected by contaminated blood that it was not separate to its members. It was its members. It was run by patients for patients. Those who formed the Executive Committee were individuals who shared with the members they served the same group of doctors and

such information, advice, choices and treatments as were made available to them all. They suffered or watched the children they loved suffer the same appalling treatment-induced illnesses and deaths and the Society doesn't seek not to be judged. It does seek to be judged in this light.

Throughout the Inquiry, the Society and its trustees and staff, many of whom are here today, have made it their mission to listen and build bridges while remaining sensitive to those who need distance from it. That any member of the bleeding disorder community should need such distance remains a source of profound sadness to the Society, and it hopes to be able to rebuild trust and work together in the future. The Society would encourage anyone who has not had the opportunity to do so to look at Kate Burt's statements, and those add to the statements made by others who have provided evidence to the Society.

On behalf of everyone at the charity, Clive Smith, who you know and who is here, and Kate Burt, who you may not know but who is also here -- please do go and say hello. Kate, perhaps you'd like to put your hand in the air.

We hear you and we invite you and hope you will feel able to talk to us or continue to talk to us. The

Society hopes that this period of time between now and the report's publication and the setting up of the compensation framework and the legal and psychological support structures that need to accompany it could be a time of healing.

It would like to pay tribute to the infected blood campaigners who have given such a large part of their lives up to the fight for justice. These include the Manor House Group, the Birchgrove Group, Tainted Blood, the contaminated blood campaign, positive women, Haemophilia Action UK, Haemophilia Scotland, Haemophilia Wales, the Scottish Infected Blood Forum, Haemophilia Northern Ireland, Friends and Families of Haemophilia Northern Ireland, the Fatherless Generation and Factor 8, alongside many other groups and charities and individuals without whom we would never have seen this Inquiry take place.

We particularly remember those campaigners who did not live to see the end of the Inquiry. Thank you.

We turn lastly to the future and to recommendations. We've covered these extensively in written submissions and I've got written down on paper in front of me a number of lists.

I will summarise things as briefly as I can but our submissions were supported by the results of a survey of

the membership and their priorities and needs. One of the things that those responding to the Society's survey were clear about -- and I think this is something that everybody here will share -- is the fact that they were very clear that annual payments must continue. The Society was pleased to see that Sir Robert's report is called *Compensation and Redress for the Victims of Infected Blood*. It agrees with Mr Snowden that language is important. Use of words such as "hardship" and "recompense", and so on, have led to confusion about the purpose of monies made available, restrictions on payments out, and the widespread feeling among applicants that they have had to beg for scraps.

It is appropriate for the new financial payments, which will be made as a result of this financial Inquiry, to be called what they are: compensation.

The Society repeats what it's called for in submission to any compensation scheme that's established and here comes the list:

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

To continue existing support schemes alongside a compensation scheme;

Compensation to be sufficiently personalised to ensure it reflects the loss and damage served by an individual with a framework that should include set tariffs to allow a faster but robust system for those who want to take that route;

A fast track to an emergency payment for those in urgent need;

An upfront lump sum to be paid to the infected and affected community in advance of the full amount;

A clear, straightforward process which is easy to use;

Specialist support for people making applications, particularly where evidence has been lost or destroyed;

The claims should be approved on the balance of probabilities with the starting point being that the evidence of the applicant is believed; total parity across devolved nations;

A compensation package funded by the Westminster Government because this scandal happened before devolution;

A system which allows transfer of information from supported administrators to schemes to reduce the burden on claimants to provide information;

A transparent appeal system;

Previous payments not to be taken into consideration;

Inclusion of non-financial elements in the

compensation package, such as psychological support, health passporting and Government underwritten life insurance;

Financial advice available to all receiving compensation;

An individual assessment by a judge-led panel with representation from the community, if people choose that route; and

To widen eligibility to include impact from viruses or exposure outside the current support schemes, such as hepatitis B and vCJD.

Accessibility. A significant number of eligible Society members are older. They don't have smartphones. They don't have tablets or computers, they prefer to get information on paper in the post and they are traumatised by their infections. They've had to fill these forms out time and again and they can't face the idea that they'll have to do it once more. They don't want to have to handle any more administrative tasks themselves. They need help.

The Inquiry has heard a substantial body of evidence about the hurt caused by the administration of the schemes, the future arrangements must be characterised by respect and compassion.

UK support -- sorry, the Society supports the

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 the risk that vulnerable individuals will be left to cope alone again. That mustn't be allowed to happen. It is unfortunate that the start of the new framework will come at a time when the country's finances are in poor shape and public sector workers are on strike. The Society hopes that the Inquiry will make it clear that one of the lessons to be learned from the contaminated blood scandal is that denial of injustice and postponement of financial responsibility while generations suffer is a false economy. Late compensation costs more than timely and adequate redress when people are ill and dying, and carers and dependants are most in need of the money, and the Society hopes, Sir Brian, that you might be able to get across the very simple message: delay doesn't pay.

Non-financial recommendations. In common with many of the other Core Participants, the Society made recommendations on public inquiry reform, redress for avoidable harm, consent, continuing scrutiny of recommendation implementation, the Irish experience,

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 a little more about treatment and information for the bleeding disorder community, and something about public inquiry reform, redress, consent and candour. Before turning to those areas, a word about follow-up and delivery.

At the beginning of these submissions, I spoke about the need for a formal framework to ensure that the Government's feet are held to the fire. The Patient Safety Commissioner Dr Hughes has said that her motto is "Speak up, listen up, follow up". It may be that for matters within her remit, it could be appropriate to recommend that she be entrusted with the work of following up delivery, perhaps including regular progress reports. Alternative mechanisms include adjourning the Inquiry, post-publication of the report, with the recommendation that the chair review implementation of accepted recommendations within a given time period, and the possibility of a supplemental report commenting on the success or otherwise of the implementation in the interim, plus or 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 affected 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 hepatologist 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 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 with Ms Richards and Ms Scolding, King's Counsel, yesterday, the Society has very recently received 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 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-existent 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 experimented upon. Further, that patients were given the best treatment available, and anyway, even if they hadn't, all the lessons had been learned.

The history of inadequate co-operation with Archer, the defensive, insufficiently objective self-sufficiency report, and the delay in setting up this Inquiry are all evidence that a clear and transparent mechanism for making decisions about when to hold a public inquiry, or a non-statutory review, would be extremely helpful if not required. The Society suggests a recommendation is made that there be an independent body with the power to convene a public inquiry -- that would require an amendment to the Inquiries Act -- or a recommendation to the relevant minister that a public inquiry be held.

Such an independent body could be charged with applying transparent criteria to assess the circumstances in which inquiries or reviews must be held. And it could collate them so that there's a central repository of recommendations, monitor which recommendations are accepted by Government and how the implementation works out, and, in appropriate circumstances, require inquiry chairs to review such implementation as there has been.

The Society also feels that there is a specific need to say something about a requirement that the decision-maker meets victims in person.

Sir, you've heard evidence from Mr Burnham and Mr Jeremy Hunt that both were actively counselled by civil servants against meeting in person those who were campaigning for public inquiries. You'll remember I think -- I think it was Mr Hunt said he'd been counselled against meeting Nazanin Zaghari-Ratcliffe.

The Society considers that this sort of a meeting is essential. You've heard at least three examples of individuals being profoundly moved and having their views changed by meeting infected and affected people: John Moore, who we've already discussed, in 1977; Mr Hunt in his interaction with Mr Dorricott and his family; Andy Burnham meeting Eleanor and Fred Bates and realising that something was very wrong. There's no substitute for the decision-maker hearing in person from those who are suffering and seeking justice. There shouldn't be a filtering by civil servants.

It submits that however decisions about whether to hold or not hold a public inquiry or statutory review are made in future, an in-person meeting should be a mandatory part of the decision-making process.

Candour, redress and consent. These three overlapping concepts, which together form a virtuous circle, if you remove any one of them, the circle collapses. Jeremy Hunt and Baroness Cumberlege are

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

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

In 2.51 she said this:

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

where healthcare professionals have no reason to fear being candid and telling the truth to their patients."

Her solution was a redress agency: a non-adversarial process with determinations based on avoidable harm, looking at systemic failings.

The Government rejected that recommendation outright. Its July 2021 response to her report was that those suffering from sodium valproate and pelvic mesh wanting compensation would have to bring legal proceedings. Exactly the same response it gave to you over AIDS in the 1980s and over hepatitis C in the 1990s.

One of the reasons it rejected the recommendation was, said the Government, that it already has the ability to set up support schemes. And the best example that it could come up with was the -- this is how it phrases it -- "infected blood support scheme". The only inference that we can draw from the Government's reference to that -- and we assume that that is a reference to EIBSS, and this is a reliance in July 2021 on EIBSS as some sort of model of good practice -- is that the Government actually thinks that the infected blood support schemes provided or provide an example of redress done well, so that we don't need to change anything.

That suggestion flies in the face of all the evidence heard in this Inquiry by those of you who utilise the schemes. It suggests that the Government doesn't know about or hasn't been listening to the evidence of users given to this Inquiry. You've provided abundant evidence of the adverse effect on you of the lack of any financial assessment of your losses and needs, psychological harm caused by different treatment of the infected and affected in the devolved nations, divisive means testing, needless complexity and opacity, applications being dealt with and basic errors being made or applicants being disbelieved, onerous requirements for evidence, unexplained exclusion of bereaved parents, the lack of any proper voice of the infected and affected within the administration, and the conflict between users in dire need and administrators who hold back large reserves of monies intended to be paid out.

Second, the Government's July 2021 response failed to acknowledge or even refer to the oral evidence of Mr Hancock. He gave evidence to the Inquiry on 21 May 2021, and he accepted that the trusts and schemes had been run without there being "a proper process around coming to a fair and just way of ensuring that people are supported", so it's surprising that there's

no reference to that a couple of months later when the Government responded to Cumberlege in July.

The Government has set up two litigation gateways for those harmed by the medicines and devices that Baroness Cumberlege looked at. You can go down the normal route where you instruct your own lawyers, and they get on with the business of litigating. Alternatively, you can ask the Government to investigate, and this is what happens. The Government's solicitors will provide the Government with a report. The Government will look at its own report, and it will either admit liability and pay compensation to you, or it will deny liability. Either way the Government will not release its report to you, and you can see these gateways set out on a web page resolution.nhs.uk/vaginalmesh.

That approach is consistent with an adversarial system in which each side can claim privilege and withhold the expert advice it's received. It's a legal process geared towards establishing blame, not an open and transparent patient safety driven process aimed at establishing the harm that's been caused, how it could have been avoided, and what needs to change.

And you have to wonder, where the report obtained by Government through its alternative litigation gateway

tells the Government that it needs to admit liability and pay compensation, why should not the person who has been harmed by its negligence see that report? One answer could be a concern by Government that that individual might then share that report with other injured patients.

So this is not a system for learning; it's a system for being defensive.

There are signs that the Government may be having a change of heart. In this Woman's Hour interview on 3 January, Dr Hughes told the BBC that the Health Minister has asked her to look into redress for the Cumberlege victims, if I call them that, and Dr Hughes is looking for a commitment from the Government that it will provide that redress. One didn't get the impression that she'd had the answer she was looking for at that stage.

But these patients shouldn't have to fight the NHS and the Government any more than you should have to. A fair, predictable, swiftly responsible system for 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 Sir Robert's detailed scheme could be minimised for

others in future, because there would be well-run schemes that could be adapted quickly to suit the needs of different groups of people avoidably injured by systems failures.

Consent. The Cumberlege Review's findings demonstrate that there's still quite a lot going wrong. Doctors are too ready, still, to make assumptions about what patients want, or adopt the position that they know what is in their patients' best interests. They're still overselling benefits, underselling burdens, and not being clear enough about that which is uncertain and that which is unknown. They're particularly bad about giving balanced advice about medical products where there's no consensus about the risks, and therefore no consensus about how you should weigh up the benefits and burdens.

The Society notes, for example, paragraph 5.41 of *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 and patient stories of harms have been overlooked".

The Society invites you, sir, to consider the informed consent section of the Government's response to that review and consider whether its actions for improvement go far enough.

Publication of this Inquiry's report might also provide an opportunity to recommend ongoing monitoring of implementation of, for example, the National Institute for Health and Care Excellence's shared decision making guideline, and importantly, the extent to which patients are routinely made aware that they have the right to record a discussion with a doctor if they wish to do so, and the extent to which patients are taking up that opportunity and measure the effect. A study on those matters could be beneficial.

The Civil Service. A few words about the Civil Service, which has not been an ally to those harmed by infected blood in your search for truth. We'd like to say an extended bit, if we might, about the Government's 2006 self-sufficiency report.

The Society has been dismayed to read the statement of Peter Burgin, the author of the Government self-sufficiency report -- the original author, I should say -- and his statement is dated 15 December 2022.

Since it was made available the day before written submissions were due to be filed, it wasn't a matter

that we were able to deal with in written submissions.

This is the story. He completed his report and delivered the final draft on Christmas Eve 2002. He says in his statement that in preparation for his report he had a meeting with the Society, and he describes that as having been extremely helpful. After he delivered his report, the Department of Health paid some consultants -- we don't know who or very much about them -- to amend the report. The amended draft was sent to clinicians and others -- again, we're not sure who -- for their comments prior to publication. It was not sent to the Society prior to publication.

The Department published the report which it had had amended without telling Mr Burgin, and Mr Burgin only found out that the report, the original version of which he drafted in 2002, had been published in 2018.

If you look at his witness statement, which I'll recommend, WITN7485001, he provides a table with a comparison of what he wrote in 2002, and the amended document was published in 2006. That effectively shows that his report was, to use the modern expression, sexed up by the consultants employed by the Government. The references to the Society appealing to Government not to ban imports of American imported product despite allegedly knowing of the risk of NANB hepatitis were

added without his knowledge.

So far as the Society can see -- we could be wrong but don't think so -- Mr Burgin's statement to this Inquiry is the first time that the then professor Frank Hill is identified as a contributor to his work. There are footnotes referring to Mr Burgin's interview with Chris Hodgson and his interview with Dr Mark Winter, and there is a reference to reports from Dr Hill, but no mention of an interview with him. We assume, but we don't know, that when Mr Burgin approached Dr Hill to assist with the self-sufficiency report, Dr Hill did not disclose to him the fact that a negligence claim brought on behalf of one of his child patients, whom he had infected with HIV through contraindicated prescription of Factor VIII rather than cryoprecipitate, had been settled at trial in 1992.

Had the published self-sufficiency report included a list of contributors, the Buggins family, and perhaps the Society, would have had additional grounds to challenge it. Had Dr Hill learned any lessons from the case brought against him and had he been open and honest with Mr Burgin, Mr Burgin would have been given direct evidence that at least one cohort of child patients may not have been given the best treatment available at the time but, instead, it was possible for Professor Hill to

cover up his wrongdoing and mislead the original author of the Government's own internal review and, I say again, an internal review that it did not share with the Society in draft before publishing it.

Importantly, we also see history repeating itself. It was through the good offices of Elisabeth Buggins that it was drawn to my attention why it is likely that Mr Burgin went to Professor Hill. We don't know and so it may be that you wish to ask Mr Burgin, I don't know. Mr Kennedy, King's Counsel, has been kind enough to confirm the facts for me, but in 2002, Professor Hill, as he then was, was the chair of the UKHCDO, so it seems likely that he was interviewed in his capacity as the head of that organisation.

One sees alarming parallels with what happened with Professor Bloom, who, as a result of being perhaps the chair of the UKHCDO, was then asked to sit on almost every other committee and had a finger in almost every other blood products pie, and we see the damage that that overreliance on one single individual caused.

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

The whole history of that report, its amendment, its 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 created 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, again, from the Bishop Jones' 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."

Thank you very much, all of you, and thank you, Sir Brian.

SIR BRIAN LANGSTAFF: Thank you, Ms Gollop.

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

(12.55 pm)

(The Short Adjournment)

(2.00 pm)

(Proceedings delayed)

(2.13 pm)

SIR BRIAN LANGSTAFF: Apologies for the slight delay; there were some technical issues that had to be sorted out.

Mr Kennedy.

Closing Statement by MR KENNEDY KC

On behalf of the United Kingdom Haemophilia Centre Doctors' Organisation

MR KENNEDY: Sir, thank you. Actually, the apology should come from me because it was my technical difficulties which hadn't been sorted out.

SIR BRIAN LANGSTAFF: Well, that's very noble of you.

MR KENNEDY: Not at all. It's perhaps a positive place to start.

Sir, as you know but others don't, or may not, my name is Andrew Kennedy. I appear at the Inquiry on behalf of the UK Haemophilia Centre Doctors' Organisation, instructed by Tania Francis at Hempsons.

Sir, can I start where I started in writing, and just say this: the UKHCDO -- I'm going to use that abbreviation throughout -- recognises the tragic events of the 1970s, the 1980s and the 1990s that gave rise to the need for this Inquiry. The suffering of the infected and affected has been and must remain at the forefront of the work of your Inquiry. That remains the case today, as it did at the start.

UKHCDO wishes to express the utmost sympathy for the infected and affected, many of whom continue to attend

Haemophilia Centres across the UK today.

Since its inception, UKHCDO, as an organisation, has attempted to support and advocate for people with bleeding disorders, and this remains the main focus of the Organisation today. So whatever factual determination the Inquiry may reach as to the events of these decades, the reasons for decisions made and taken, and any culpability of individuals or organisations, it should at all times be remembered that the infected and affected were the innocent victims of events over which they had no control.

Reading the written submissions of the Core Participants on behalf of the infected and affected, listening to the oral submissions of my learned friend Mr Snowden and my learned friend Ms Gollop over the last two days, watching the loving and moving tribute to Lee shown on Tuesday only serves to reinforce this point. The current executive of the UKHCDO is acutely aware of the suffering of those innocent victims, and, sir, it is determined to take to heart the lessons to be learned from your report and to implement fully any recommendations that you may make.

Sir, you designated the Organisation as a Core Participant on 19 October 2018, following the acceptance of an invitation which the Inquiry, I anticipate on your

direction, had proffered. Hempsons were instructed just before Christmas 2018, and I was instructed in the summer of 2019. Hence neither Hempsons nor I, nor indeed the UKHCDO, appeared at the opening of the Inquiry on 24 September 2018.

But present today is Professor Pratima Chowdary, who is the current chair of the Organisation and the co-chair of the National Haemophilia Database. She sits towards the back of the room.

She is also, sir, as you may recall, the author of the NHD statistics report that was provided pursuant to the Inquiry's Rule 9 request.

At that opening hearing, my learned friend Ms Richards noted that the Organisation had given the Inquiry unrestricted access to all of its material, physical and electronic, which she described as a huge repository of material. Accessing that material has involved or included the Inquiry's investigators attending the National Haemophilia Database in Manchester to inspect its paper archive.

The volume of material is perhaps unsurprising given that the Organisation spans the entire period of your Inquiry, so it spans the period from the late 1960s through to today. And as, sir, you know, the database has collected statistics for the entirety of that

period.

As part of the Inquiry's disclosure exercise, we have considered almost 6,000 documents at the request of the Inquiry. That is 6,000 documents emanating from the Organisation. We have taken no objection to disclosure of any documents, and our comments to the Inquiry have been confined to proposals for redactions.

As a consequence of that exercise, the Inquiry has made available to Core Participants of the order of 2,800 documents which emanate from the UKHCDO. And those documents have been available to Core Participants on Relativity.

If you do the simple exercise of trawling through who has disclosed what, you will see the UKHCDO's disclosure is amongst the largest disclosure of all of the Core Participants and, indeed, all of those who have disclosed material to your Inquiry.

Can I, sir, reiterate, at the outset of my observations, the UKHCDO's gratitude to the Inquiry. As we explained in paragraph 7 of our submissions, our written submissions, much of the focus of the Organisation during the evidence hearing phase has been on the preparation of the report to answer the Inquiry's Rule 9 request for a UK-wide report on bleeding order *(sic)* statistics.

I don't know whether, sir, you've seen the letter making the request but effectively the letter said: Please could you provide an equivalent report to the report that you provided to the Penrose Inquiry but for the entirety of the UK.

For the sake of the transcript, and as I say, the author of which is Professor Chowdary, the report is to be found at WITN38226016.

This was a very substantial piece of work. Again I say, unsurprising, given that the period that we looked at was one of more than 50 years, from 1969 to 2020, that the Inquiry's request was that the data be set out on an annual basis, disaggregated, as the expression used in the letter, to centre, and specifying the amount of each product used.

Those who have read the report and, more particularly, been through the spreadsheets, will appreciate the extent of the exercise.

Sir, whilst much of the data -- and this is my gratitude on behalf of the Organisation -- was already computerised, some of it was not, and the Organisation is grateful to the Inquiry for the assistance it's been able to provide to enable the final digitisation of the database, and perhaps more particularly for facilitating the exchange of information with NHS Digital and other

organisations, and the reality is the Inquiry has been able to cut through red tape where we have not been able to. That has allowed us to complete the database, if I can put it like that, with up-to-date information, particularly about cause of death.

Sir, as we say in our written submissions, towards the end at paragraph 276, our suggestion is that the report demonstrates the value of the database. I acknowledge that some have expressed concerns that their data is held, whether by the database or at all, but we would hope that, having now seen the report, those who have been concerned can now see the merit or at least some merit in that data being collected and being made available.

Sir, we addressed issues of consent to the holding of data and access to data in our written submissions in paragraphs 53 to 64. I do not propose, unless you wish me to, to repeat those now, but I would direct anybody to those paragraphs but, more particularly, to what is said on the UKHCDO website about addressing information -- sorry, what is said on the UKHCDO website about addressing the information that is held and how to go about accessing it.

We believe that the database is without rival across the world. Sir, we referenced in our written

submissions European research, including about the incidence of such databases, that showed in 2008 only a bare majority of European countries had a national haemophilia patient registry, as it was referred to in that paper.

By that stage, the database was entering early middle age. We suggest that the value is underscored by the work undertaken by your statistics expert group, and in particular, the complex modelling that it had to undertake to make an assessment of the impact of infected blood on transfusion recipients, for whom there was no equivalent longitudinal data. In simple terms, sir, all one has to do is to compare the accuracy of figures that the group provided for HCV and HIV infections, and also for deaths, for those with bleeding disorders, against those for people with blood transfusions, and you'll recall the breadth or the range of possible accurate answers to the latter.

Sir, can I then just say one or two more words about the balance of our involvement with the Inquiry. Aside 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 evidence or a combination of the two.

The first sought clarification of information held by the database concerning a relative of a witness who had given a statement to the Inquiry. It was a very detailed enquiry in relation to "Why does it say [X] when I believe [Y]?"

I don't wish in any way to diminish the import of the request but it was confined, as I say, to a detailed enquiry about the entry for one patient on the database.

The second request that we had related to criticisms made by Jason Evans, primarily about the legality of data held on the database and information sharing, and also the criticisms that are set out in the Tainted Blood document.

Those were the two Rule 9 requests that we received in addition to that for the statistics report. Sir, a number of clinicians have provided statements to the Inquiry about UKHCDO.

SIR BRIAN LANGSTAFF: I think the orchestra are leaving.

MR KENNEDY: I was going to recount a story about that but I won't do it now, it's not the time or place.

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 capacity in this sense: their statements were prepared by their defence organisations or by, we anticipate, their employing trusts. The UKHCDO legal team was not involved in the preparation of the statements, and we were told when we enquired about the Rule 9 requests that they were confidential to the clinician.

Sir, the written evidence you have received in relation to the UKHCDO has been prepared without any input from the UKHCDO legal team. Now, that may well be a good thing; it certainly would answer any suggestion party line taken by the Organisation.

But it follows also from that that the witnesses who have given evidence before you, none of those have been, as my learned friend Ms Grey put it yesterday, supported by, in this case, the UKHCDO legal team.

We explain in our written submissions that the current executive of the Organisation has concluded that it should not take a position on the issues that you have to decide or the factual findings that you should make. I am conscious that there was disquiet yesterday when that stance was explored with my learned friend Ms Grey, and I set out, if I may, the rationale for that position.

There are three points. First, the UKHCDO is a professional membership society. The Organisation is, in effect, the sum of its individual members. It does

not have a corporate identity or a corporate memory in the same way that perhaps an NHS Trust might have. Second, the current executive, and indeed membership, self-evidently, is not made up of the same individuals as the membership at the material time in the 1970s, '80s and '90s and, much as the Inquiry has faced challenges in obtaining accurate and reliable evidence in relation to matters which occurred over 40 years ago, the UKHCDO's membership and executive is not in a position to comment definitively on events about which they have little or no firsthand knowledge.

I underscore the point I made to you a moment ago, sir, that those who have spoken about the UKHCDO have done so with their, if I can put it likely this, clinician hats on rather than their UKHCDO hats on.

Perhaps more importantly than either of those two points is this: the current executive and the wider membership of the Organisation have a continuing therapeutic and professional relationship with some of the infected and affected, and with others with haemophilia. It is felt that for the Organisation to take a position as to the merits of the issues with which the Inquiry is concerned would be potentially to compromise that continuing therapeutic relationship.

Sir, it is for those reasons that is the rationale,

as I put it, for the stance that we have taken of not seeking to comment on what findings you should make or indeed not make.

Sir, can I, acknowledging what I have just said, just draw your attention to one or two matters, with the greatest respect, about the fact-finding exercise, and I do so conscious of what my learned friend Mr Snowden said yesterday about the passage of time. I don't think it can be said of the Organisation that we can't blame something which is -- lay the blame for something which is our fault, and I'm very conscious of the point that he made to you, with which I agree, which is that you are well familiar with dealing with issues of fading memories, so I say no more about that.

But, sir, the passage of time -- or rather with the passage of time come developments in practice and changes in prevailing standards. The Inquiry may wish to acknowledge and take that point into account.

I would then, if I may, respectfully adopt what the 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 paragraph 1.24.

They said this:

"The first and fundamental point is that it is now potentially impossible to trace over the decisions of the past ..."

They give the example in relation to the risk of AIDS in the 1980s:

"... without being influenced by the awareness of what comes next. Rather like trying to retrace one's way to the centre of a maze, which has been successful negotiated, the route on the second journey into the maze will be influenced consciously or subconsciously by the previous successful trip or roadmap. Less weight or attention given is to blind alleys or false starts that seemed appropriate routes, even promising ones at the time, but were later shown to be mistaken. Time exploring them is more likely to be discounted. Equally it may be harder to give credence or weight to the intentions and plans of those involved at the time when later shown to be flawed."

Again, sir, I acknowledge that is something you will be familiar with overcoming, but I just, as I say, endorse that point.

SIR BRIAN LANGSTAFF: Well, it used to be, early in my career when I dealt with quite a lot of industrial injury accidents in practice, I know some advocates would say to a judge, "Well, look at the changes there have been in practice now as a result of this accident. That should have been done beforehand", and it was never a proper answer.

MR KENNEDY: No.

SIR BRIAN LANGSTAFF: It might indicate, in some circumstances, depending on the context, that more could have been done, but it might not.

MR KENNEDY: It wasn't a complete answer.

SIR BRIAN LANGSTAFF: No.

MR KENNEDY: No.

SIR BRIAN LANGSTAFF: So it's a question of context, and context, I think, is knowing, as best one can, it is the past and the past, as someone has said, is a foreign country. But it's understanding, trying to understand, as best one can, what the context was and bear in mind what, at the time, the context should have been, if it wasn't.

MR KENNEDY: Indeed. Indeed.

SIR BRIAN LANGSTAFF: It's a complex judgement.

MR KENNEDY: It is, indeed. We refer to it as context in our submissions and indeed that is what it is.

Sir, I say this with a little trepidation, given what Mr Snowden said on Tuesday, we undertook the exercise of setting out a form of presentation -- I use a small "p" rather than a large "P" -- from the

presentations that CTI have produced, of the minutes of the meetings of UKHCDO and some of its working parties to assist the Inquiry in this sense: by placing all that material in chronological order and in one document, with the guide to where it is to be found on Relativity.

We hope it is more than just a chronology. It was, however, consciously a summary and nothing, sir, should be taken from the amount of detail or the lack of detail with which we have dealt with events in that part of our written closing.

It is intended to be neutral. It includes material that is both positive and negative, so far as the Organisation is concerned. So if it speaks, for instance, to the preference expressed by directors in the early 1970s for imported concentrates. It speaks equally to the views of the directors and the Organisation that self-sufficiency had to be achieved and had to be achieved soon, and we've endeavoured to strike a balance as best we can.

My learned friend, Mr Snowden also said that we'd said nothing about the Heathrow meeting in January 1983. He is correct. I simply recorded that it had happened. That was for the simple reason that we believe it was an event that the Inquiry had considered in depth, and the significance of which was largely obvious.

We simply, therefore, place the meeting in its chronological context with other meetings of the Organisation, so as to permit you, sir, to take a longitudinal view.

Sir, we set out the origins of the Organisation in our written submissions. We explained that in the absence of direct evidence we've drawn information from material available on Relativity, some of which is from our archive. I don't propose, you'll be glad to hear, to cover that ground orally. I will just say of the Organisation: whilst we acknowledge that criticisms have been and may in the future be made of the Organisation and how it has acted in the past, and that it has been slow to act in the past, there is countervailing evidence that shows that the Organisation has at times been a leader and not a follower.

I've mentioned in my submissions the database. I would also mention its attitude towards the promotion of comprehensive care. And again, sir, you may recall that the 2008 European Inquiry stressed the importance of comprehensive care.

I would add a third point, and it is this: it is the introduction of professional peer review in Scotland and Ireland in 1991, and England and Wales in 1992 and 1993, and the Organisation believes that this is one of the

earliest examples of professional peer review in the NHS.

Sir, to give a chronological landmark, if I can put it like that, the National Institute for Clinical Excellence, what we know as NICE, now called the National Institute for Health and Care Excellence, that was set up in 1999. Now it's not a direct comparator but maybe it will give you a chronological landmark. So it's a little bit short of a decade behind the introduction of peer review by the Organisation.

Sir, the Organisation aims to consider the contemporaneous uncertainties in managing individuals with bleeding disorders, to enhance the understanding of inherited bleeding disorders and their management, and to improve the quality of care for this group of people.

As is typical of such professional societies, the UKHCDO seeks to provide guidance where reliable evidence is available. In the absence of good evidence it provides a forum for examining existing information, exchanging opinions and experience, and articulating a consensus on the potential approaches to deal with challenges reported in routine clinical practice. It encourages collaboration, both nationally and internationally.

As we have pointed out in our written submissions, sir, these deliberations also permit the identification of unmet needs or service deficiencies.

Since its inception, the membership of the Organisation has been drawn from all four home nations. This continues to be the case today, despite devolution. Hence the Organisation seeks to improve the quality of care of people with bleeding disorders, irrespective of the policies and priorities of their national commissioners and providers.

That said, as we say in our written submission, healthcare policy is the province of the UK Department of Health, NHS commissioners and other designated bodies and their equivalents in the devolved nations.

We seek to influence healthcare in clinical policies through interactions with members of these organisations and other national and regional bodies. But as we explain in our written submissions, we don't have a role in the accreditation or ongoing assessment of doctors. That falls to the General Medical Council and the Royal Colleges.

Sir, can I address one or two points arising from the submissions of other Core Participants, and then I have some comments to make about recommendations.

One recurring theme was that UKHCDO was dominated by those at its head or by the largest Haemophilia Centres.

Before looking at that briefly, can I just observe this: from the outset, so that's back to Rosemary Biggs in 1968/9, and the early meetings of the 1970s, the Department of Health, then the Ministry of Health, and the blood transfusion centres, were regular attenders at UKHCDO meetings, and the Department continued to be an attender at meetings. And I've, I hope, captured that in that part of our written submissions.

Similarly, The Haemophilia Society was an early and regular attender at the annual general meeting. The first record that I can identify is 1 November 1974, the Relativity reference is HCDO0001017, but again we capture that in our written closing.

My learned friend, on behalf of the Leigh Day Core Participants, and I hope they'll forgive me if I give them that name, described the Organisation as a "voluntary and unincorporated association". That is SUBS0000059_210 at paragraph 26, where my learned friends wrote this:

"It proved to be significant that this de facto leadership organisation was a voluntary and unincorporated association, essentially dominated by the largest and most influential centres."

We certainly would agree with the first part of that proposition, in other words a voluntary and

unincorporated organisation, and that remained the case, sir, as you will be aware, certainly up until the early '90s with charitable status and the limited company.

So that was the status for much of the period you're concerned with. Whether, on the other hand, it was -- and I would add "inappropriately" -- so whether it was inappropriately dominated by the largest and most influential centres is a matter, sir, that you will have to wrestle with. I just make this observation: we've set out how the Organisation in its meetings changed over time in paragraph 66 and following of our written closing and you will have seen that, for much of the period, the Reference Centre Directors, as they were called, met at least biannually and all the directors once a year.

It's perhaps unsurprising, if the directors of the larger centres played a greater role for the simple reason that they attended meetings three or perhaps four times a year, whereas the directors of Haemophilia Centres or associate centres only once a year.

That is for understandable reasons: a meeting of 10 or 12 is easier to organise, certainly in pre-Zoom days, than a meeting of 78.

We know from personal experience that, in organisations such as this, it is often the case that

one personality or one or more personalities may dominate. But whether the larger centres inappropriately dominated, as I say, sir, is something you may want to wrestle with. You may bear in mind that their directors will have brought greater experience, if not greater expertise, greater experience coming from treatment of a greater number of patients.

My learned friends on behalf of the Thompsons Core Participants make a similar point. They say the UKHCDO was a club dominated by those at its head. In their submissions, which is SUBS0000064_0247, at paragraph 4.55, they said this:

"In the evidence heard by the Inquiry from Government Ministers, the 'clinical freedom' [which they put in inverted commas] which was championed as a means of the Government evading ultimate responsibility when things went wrong in the medical sphere. In fact, given that the individual haemophilia clinicians were bound by the diktats of this group, what is more, Dr Winter described the group as being a form of club where the views of the few at the top predominated. This approach to centralised decision making by a few core individuals had important ramifications for the care of haemophilia patients generally, but also as for the formulation of policy in the care of haemophiliacs in Scotland in particular."

I just say this: the observation of "dominated by those at the top" we leave to you but we would just, with respect, correct what my learned friends say when they attribute that expression to Dr Winter.

Lawrence, if we can just bring up Dr Winter's evidence. He gave evidence on 1 October 2020 and my learned friend, Ms Richards asked Dr Winter the question at the bottom of page 114 of the transcript. Thank you, Lawrence.

She said:

"Can I ask you one further question about UKHCDO, not at any one point in time, but in the knowledge that you are about to become a member, in the end of 1983, when you became a director in Kent.

"Professor Savidge, who you obviously dealt with quite extensively over the following months and years, in his evidence to the Archer Inquiry was very much critical of UKHCDO. He said it was run pretty much as a club by the ten or so main players, and there was something of an information vacuum for directors in particular of smaller centres."

She asked him whether he would agree with that, whether that was his experience once he became a director.

Forgive me, I paraphrase her final question. But Dr Winter's answer is, we would suggest, informative. He says:

"I don't agree with that. I think we should state UKHCDO was generally regarded by the other haemophilia societies and doctors and other countries as actually being a model of its kind. There isn't really any other country where haemophilia doctors came together and collaborated to such an extent that every patient with an inherited blood disease in the country was registered, we knew the number of patients with the condition, we knew the severity of the condition, we knew whether they had an inhibitor, we knew whether they were on home treatment, we knew whether they were alive or dead. No other [patient] had information like this. And every time you went to a World Federation meeting, people would say, you know, your system you have in the UK is light years [I suspect he means 'ahead'] of what we have in our country. We have nothing like it.

"Then, in addition to that, as we've seen already, it was a very active organisation, in addition to all the day-to-day work we were doing. At any one time, there would be six, seven, eight working parties in specialist areas. So I thought the UKHCDO was a very good thing. Of course, there were personalities

involved, of which Professor Savidge was a large one."

Thank you, Lawrence.

Sir, my learned friend Ms Gollop on behalf of The Haemophilia Society, says in her written submissions on a number of occasions that the UKHCDO was the most authoritative body or voice in the UK.

We suggest that is neither surprising nor sinister. Certainly objectively. It was formed of most if not all doctors treating haemophilia on a regular basis. That is, it was a group sharing a common interest or concern in the treatment of a discrete disease. And we would anticipate that the same might be said of a number of equivalent professional societies, both then and now, where the number of patients suffering the disease is such that it would not support more than one professional society.

That said -- this is my comment objectively -- that said, we would entirely accept that with that status comes responsibility, and the Inquiry will have to address whether the Organisation did or did not discharge that responsibility.

Another point that is made is that the guidance that was issued by the Organisation was not mandatory. In particular -- and it's said by the DHSC -- sorry, forgive me, the DHSC mentioned the evidence of

Dr Walford, that the guidance issued in June of 1983 was weak because it was advisory rather than mandatory.

And, sir, perhaps I should just fill in the dots. So the guidance that I'm referring to is that of 24 June 1983. I'm assuming that everybody is so invested in the detail of this case that they will know what I'm referring to, but it was the first guidance that came from UKHCDO that bore in mind the AIDS -- bore in mind AIDS.

In terms of what the Organisation could and could not achieve, we would agree with Leigh Day -- the Leigh Day Core Participants -- when they say that we could not have granted ourselves -- I paraphrase -- could not have granted ourselves a power to make -- forgive me -- to make binding clinical recommendations.

That is SUBS0000059_0212 at paragraph 33.

And we agree with what is self-evidently implicit in that statement, which is that we didn't have that power.

Plainly, sir, it will be a matter for you whether the guidance that was promulgated should have been expressed in stronger terms. Both should have been expressed in stronger terms, and should have been more extensive or more expansive. But we would simply say to you, sir, that the Organisation was not in a position to mandate or direct practice, the practice or treatment provided by clinicians.

There are perhaps two relevant points to make. First, we had no power to do so. But we also had no means of enforcing a direction. And if you, sir -- I can see you perhaps mentally posing yourself a question. If you look, for instance, at the guidance issued in 1997 in relation to recombinant products, and I touch on that in my written closing, even that -- it may be said it goes further than what was said in 1983, but even that doesn't say, "You must do this". It says, "You should".

So it seems to us that the question is whether the guidance should have been expressed more strongly rather than it should have been set out in mandatory terms.

We would also just invite you to bear in mind that if this guidance was to be expressed in mandatory terms, it would have had to apply not just to Haemophilia Centres but to any hospital that might treat a haemophiliac and, indeed, arguably across the board, because it would be relevant to those receiving blood transfusions. So we would respectfully suggest that, if mandatory guidance was required, it needed to come from a body with greater and broader authority than UKHCDO.

I think acknowledging that point, the Leigh Day Core Participants suggest that the Organisation should have

sought to put -- forgive me -- should have asked for itself to be put on a statutory footing. We're not clear how that could have been achieved but it seems to us that that would have had two main drawbacks. First, the Organisation would have become simply another arm of Government or the Department, and it's unclear to us where the Organisation would have sat, for instance, in relation to a body such as the CSM.

There is also evidence that you have seen, sir, and heard, that at times the Government didn't listen to the Organisation anyway. Perhaps more significantly from the Organisation's perspective, had that happened, it would have lost its independence and it would have significantly curtailed, we would suggest, its ability to speak on behalf of those with bleeding disorders and indeed those treating them.

I'm conscious of time. I'm moving slower than I'd anticipated, but there are three examples and I will take them very briefly: one is self-sufficiency; two is, as I mentioned earlier, recombinant products, where the Department's response was "We're not going to sign off your guidance because" -- well, I'll leave others to answer the "because"; and the third example is what happened in relation to variant CJD, and what the Organisation said about the use of domestic blood at the

time of the variant CJD concerns.

Can I deal then with one matter which arises in the submissions made by the Collins' Core Participants. It's a short point, and it's just this: when discussing the issue of candour, albeit in the context of a chapter on ministers, but in a chapter that is -- a proposition that is repeated in the chapter on clinicians, my learned friends say of the article that Dr Peter Jones wrote to the Press Council -- and sir, if it helps, I can ask Lawrence to bring that up.

So this is PJON -- sir, this is the, forgive me, article letter. So this is the letter that Dr Peter Jones wrote on 6 May 1983, complaining about an article that had been in The Mail on Sunday five days before.

My learned friends say that Dr Jones was writing on behalf of UKHCDO. And it's that latter part which concerns me. There is, of course, a legitimate question for you to address as to whether Dr Jones was right to -- sorry, was correct to write in the terms that he did. And it may be -- I accept maybe that others within the Organisation shared the sentiments that he expressed in this letter. But we're unclear whether it is correct to say that this was the Organisation seeking, as my learned friends put it, to shut the story down.

I deal with, if I may -- jumping on to something that my learned friends for the Milners' Core Participants say. The reference to their submissions is SUBS0000005_0117, at paragraph 350. It's just a correction of a Relativity reference but they say this, they say:

"Nevertheless by January 1983 the issue of AIDS remained a footnote or afterthought in the minute of the meeting of the UKHCDO which took place on 8 January that year. The directors noted that AIDS was similar in its epidemiology to HPV and that the working party ought to enquire about the likely transmission of the disease through blood and blood products.

"In our submission, this lack of recognition of the severity of the risk posed is characteristic of the UKHCDO's lethargic approach to addressing emergency threats."

Sir, the short point is this: that "footnote or afterthought", as they put it, was not 8 January 1983. It was a meeting that -- the Relativity reference is this: HCDO0000003_058. That is a Relativity reference to a meeting -- sorry, the minutes of a meeting of the -- sorry, of the Hepatitis Working Party on 13 September 1982. And the date may be important for the allegation of lethargy, but you will appreciate that comes about the midpoint between the two CDC letters of 1982. A meeting of the Hepatitis Working Party took place on 19 January 1983, and it's apparent from the meetings -- sorry, apparent from the minutes that AIDS was one of the central issues that was addressed.

Sir, that we address in our submissions at paragraph 124.

Sir, two further matters which arise from submissions. One is this: it relates to the issue of clinical freedom. A number of the Core Participants have warned or cautioned of the perils of unfettered clinical freedom, and some have hinted to a suggestion that there is need for a review and qualification of clinical freedom.

Can we just say this in response to that. As we said a moment ago, sir, the practice of medicine has changed substantially over the years with which you are concerned. There have been extraordinary advances in treatment, both surgical and medical.

There has, we would suggest, also been a change in what we might term the "deference" that a patient has for his or her doctor. There are, legitimate no doubt, criticisms of a paternalistic attitude in the 1970s, and indeed later. We don't say that that has been abolished in its entirety, but I think we can all recognise

significant changes. Today's patient is much more prepared to question his or her doctor than the patient in the 1960s, '70s or '80s.

Moreover, we would suggest that in reality, with the increasing use of evidence-based medicine, the acknowledgement that departure from guidance needs to be justified and informed consent sought, the advent of organisations such as NICE means that clinical freedom -- or rather there is less clinical freedom now than there was 30 years ago. Moreover, we would caution reaching conclusions about clinical freedom based upon what I might refer to as a small sample size, so having looked at one discrete area of medicine, and equally, caution recognising, as one of your expert groups recognised, that clinical freedom permits incremental change in practice.

Then, sir, if I can just turn briefly to research. Again, much has been written and said about research. The Organisation would accept that, during the relevant period, clinicians who were UKHCDO members conducted studies in the sense of clinical trials or what might be referred to as interventional research. We would also accept that these studies were often discussed at meetings of the Organisation, and we have referred in our written submission to discussion of, for instance,

trial protocols.

I just wish to make this clear on behalf of the Organisation. That research was not conducted by UKHCDO. It was conducted by people who were members of the UKHCDO. The Organisation has confined its research -- so that is research that is published in its name -- to observational studies, that I'm going to refer to as "observational studies". It's referred to elsewhere perhaps as "audit service evaluation" or "observational research".

That observational research is conducted, or rather involves, a retrospective study primarily of data collected as part of the annual returns. Sir, I've mentioned some examples of this, and again, conscious of time, the earliest, I think, example of this is Dr Biggs's study at the beginning of the 1970s, of the incidence of jaundice and antibodies or inhibitors which was published in 1974. That is PRSE0002554, and if we look -- if that is looked up, you will see that she writes on behalf of, I think, she says the 37 directors of haemophilia centres.

There are similar examples that we cite in our submissions, written submissions at paragraph 24. For instance, again, Dr Biggs's review of haemophilia treatment 1969 to '74 and equivalent exercises

undertaken by Dr Rizza, during later periods.

Sir, I'm going to turn if I may briefly to recommendations. I've been going for an hour, I would propose, subject to your views, that I press on and finish. I don't think I will be more than another ten or 15 minutes.

SIR BRIAN LANGSTAFF: Then by all means do so.

MR KENNEDY: I should just add that I'm about the worst judge of time.

SIR BRIAN LANGSTAFF: Well, you won't be in a minority of one in that respect.

MR KENNEDY: I can hear my learned friend Ms Richards making an aside which may indicate that she and I are in the same boat.

SIR BRIAN LANGSTAFF: I couldn't possibly comment.

MR KENNEDY: I'm not going to -- we've set out our views on recommendations in writing. I'm not going to go through all of what we've said. I just want to touch on four points, two of which as will be apparent when I come to them -- forgive me, I think it's five points, two or three of which are of particular interest to the 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 say this: adopting the approach that my learned friend

Mr Snowden took on Tuesday of identifying matters which perhaps the lawyers weren't concerned about but the clients were -- and he identified natural clearers as being -- falling into that category, and I identify that too. Now, that was something that was specifically mentioned to me when we were providing our -- setting out our response to recommendations. And so what we would say or rather what the Organisation would say is particularly encapsulated in what Ms Francis and I wrote at paragraph 262. I say no more than that.

Haemophilia Centres -- I think my learned friend Ms Gollop adopted that earlier, but it's -- if I ...

I can take it in more detail if you wish --

SIR BRIAN LANGSTAFF: No, I've read it more than once.

MR KENNEDY: Then I wouldn't make you read it again.

Then just if I may, Haemophilia Centres are centres of excellence. We support the suggestions made by other Core Participants that Haemophilia Centres should be centres of excellence. It will come as no surprise, as we say in our written submissions, that the central issue is one of funding. Both, as we put it, adequacy generally, and consistency and transparency.

We note at paragraph 265 that collaboration between UKHCDO and the Haemophilia Society and the Commercial Medicines Unit resulted in a very significant saving in

the unit cost of medicines due to UK-wide procurement. It had been hoped that some of the savings generated could be used to support the development of comprehensive care. Sadly, that was not the case -- that has not proved the case.

At 264, we point out that the provision of comprehensive care is the first step to becoming a centre of excellence, and this requires a team of doctors, nurses and allied professionals. Unhappily, peer review undertaken by the Organisation has identified persistent problems securing a full complement of multi-disciplinary team members.

I can just add at this point, we've seen what one of the, I think unrepresented, Core Participants Elisabeth Buggins says about multi-disciplinary teamwork -- I don't know if she's here today, but we agree wholeheartedly with what she says.

The problems, and some of the solutions, we are highlighting in paragraph 266. In summary, commissioning must be cohesive and standardised across the UK. There must be a single service specification for all of the UK to ensure that all people with bleeding disorders have access to high quality and comprehensive care. And thirdly, any update of the service specification must be taken with the involvement

of all stakeholders, with particular focus on those with bleeding disorders so that their views are not just heard but actively addressed.

Sir, we set out at 267 a form of words which may or may not find favour.

Then, if I may, just turning to what I've described as the future of UKHCDO and the National Haemophilia Database.

Just referencing what I said a moment ago about service standards, we would anticipate that the UKHCDO will, as it has done in the past, and in conjunction with other patient organisations, play a significant role in any future discussion about service specification.

We suggest that its ability to play that significant role reflects its position, or the position that it occupies, standing between the patient and the Department, and it permits the Organisation to advocate for patients to commissioners and to the Department, and it's for that reason that we would resist any suggestion that the organisation go into a form of public ownership.

I said earlier that I mentioned three points about independence. I'll just say briefly this: had, by way of illustration, UKHCDO been within the Department tent,

if I can put it like that, in 1996 and 1997, it would not have been able to speak in the terms in which it did when issuing guidance about recombinant products -- that's WITN3289048 -- nor in the terms in which it did about plasma collection from UK donors at the time of variant CJD -- that's WITN7034006.

SIR BRIAN LANGSTAFF: Just give me that number again.

MR KENNEDY: Sorry, forgive me, WITN7034006. That is Professor Ludlam's letter to The Lancet of December 1997, where he made two points: (1) what one might refer to colloquially as Recombinant for All; and (2) to be wary of UK donors, given what was known about variant CJD.

We would therefore suggest that a recommendation that had the impact of reducing or removing the independence of an organisation such as UKHCDO, and arguably would be carried over to any professional society that one might name, would be a significant retrograde step. We note in this respect, sir, and are grateful for, the support that the Organisation receives from the Scottish territorial health boards.

At paragraph 220 of their submissions, they say this:

"The UKHCDO and the British Society for Haematology currently provide guidance on optimal treatment for people with bleeding disorders. Those organisations and the National Haemophilia Database also raise awareness of developments in patient safety concerns. This work is of great value in terms of both keeping clinicians up to date on best practice and enabling rapid identification of new safety concerns."

They give a recommendation about security of funding.

On the issue of the future of the database, just briefly this, sir: we believe that it is uncontroversial that a database should be maintained to track disease incidence, prevalence, trends and clinical outcomes and, in particular, mortality over time.

As I said earlier, that permits identification of unmet needs in the context of an evolving therapeutic and organisational landscape, and it informs healthcare planning. It is also consistent with the recommendations for the European Association of Haemophilia, as I mention in my written closing.

I've addressed you already on what we say is demonstrably the value of the database of the exercise that the statistics group had to undertake. We don't detect within the statistics group, report or the oral evidence, a particular concern about shortcomings of data selection but we do recognise what Professor Bird

said towards the conclusion of the evidence of the statistics group and we would endorse what she says about funding and about the need for greater epidemiological input.

I just say this of the database: I said earlier that we think it's a -- that -- the first comprehensive database to be established in the world. It's a model that has been adopted elsewhere. It is a tribute to the foresight of clinicians such as Dr Biggs that it exists at all. It is a tribute to those in the 1970s and 1980s who encouraged and cajoled sometimes reluctant or recalcitrant centres to submit their data. Without their work, the database might have withered and ceased to exist, as, sir, you know happened in Canada.

I acknowledge that those people I have just referred to are people who may elsewhere be criticised.

Our simple concern, or rather the Organisation's simple concern, is that a proposal -- accepting a proposal of incorporating the database within the wider NHS would expose it to the budgetary constraints that we hear and read about every day. It would render it vulnerable to compromise due to decisions about spending priorities. And we would suggest that there must be significant doubt that had the database been under NHS management for the entire period or for much

of the period with which you are enquiring, then you may well not have had access to the same extent of longitudinal data that you have received.

That said, we acknowledge that the database must adapt and change to meet future needs. There must be continued involvement of those with bleeding disorders on the management group. And again, we've touched on that in writing.

I just add one final point, which is perhaps relevant to ownership. Under the stewardship of UKHCDO, the database provides UKHCDO with access to the information from which it can generate treatment guidance. If they were divorced one from the other, it's unclear to us how the data would be accessed or whether the Organisation would end up paying the database for the data.

My last matter in terms of peer review is just this, sir: you well have seen that WMQRS, West Midlands Quality Research *(sic)* Service I think, ceased to exist during the Covid pandemic. And the Organisation is seeking to put in place arrangements for peer review or audit for the forthcoming round. I am sure that the Organisation will keep you updated if you wish as to its progress, but we cannot say anything more at this stage than we have said in writing.

Sir, can I just conclude with this on behalf of UKHCDO. I say this to Lee's family, to Andrew, who spoke on Tuesday, who is determined that something positive should come from his experience, I say it to Barbara, who spoke most movingly yesterday, to those who will speak after me from this lectern in the coming days and to the many, many more people who have given evidence before you, sir, whether on paper or in person.

We, on behalf of UKHCDO, hope that Sir Brian's report provides you with the answers that you have campaigned for and that you deserve.

Sir, thank you. That is all I have to say on behalf of UKHCDO.

SIR BRIAN LANGSTAFF: Thank you very much, Mr Kennedy. The Inquiry recognises and thanks the UKHCDO for the data it has supplied to our statistical experts enabling the Inquiry to produce the degree of statistical certainty that is available.

Thank you very much.

MR KENNEDY: Thank you, sir.

MS RICHARDS: Sir, tomorrow, then, we have in the morning at 10.00 Ms Monaghan, on behalf of the Core Participants represented by Saunders Solicitors, and then at 2.00 we have Ms Maharaj, who is the vice chair of the UK Thalassaemia Society.

SIR BRIAN LANGSTAFF: 10.00 tomorrow.

(3.32 pm)

(The hearing adjourned until 10.00 am the following day)

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