# Infected Blood Inquiry - Preliminary Hearing

26 September 2018

1	Wednesday, 26 September 2018	1	the events of today. If we truly, if you truly think
2	(10.00 am)	2	that you should have had your rights respected by those
3	SIR BRIAN LANGSTAFF: Good morning, all. Three things to	3	talking to you, then I am sure you will recognise that
4	mention before we start off this morning and, in one	4	they have a right to have the expression of their views
5	way, they are all linked by the idea of respect. What	5	heard respectfully. I'm sure you will. I said this at
6	I have heard loud and clear over the last few days is	6	the start, they are people just as we, you, everyone
7	how many of you did not feel properly respected as	7	involved are people, and I would hope that you will
8	people by those who were your doctors, or those who were	8	listen to them in silence. Applause is entirely
9	their political masters.	9	a matter for you. I don't ask for that, but if you feel
10	Respect we began with by respect for the dead and	10	you wish to give it, then do so. That's your right.
11	there are, I am told, about 40 people here today who	11	But it is their right to be heard with respect.
12	haven't been at this before. Can I just mention to you	12	I am sure that you will respect them, just as you have
13	again that if you want to show respect for those who are	13	respected, may I say, the slightly different views that
14	no longer with us, there is a memorial. It is in the	14	we heard expressed yesterday, different perspectives.
15	chapel. The chapel is not difficult to find. It is not	15	Not everyone would necessarily agree with everything
16	entirely easy, but it is not difficult to find. In the	16	that was said, but that's for you, and thank you for
17	middle of the chapel, there is a memorial which contains	17	listening to them.
18	the glass jars with messages. If you want to leave	18	Today we start listening to Steven Snowden
19	a message, there is time to do so. Please feel free, in	19	Queen's Counsel, who represents those who have
20	a free moment, to do that if you would wish to pay your	20	instructed Collins as their legal representatives for
21	own respects and have not yet done so.	21	the purposes of this Inquiry.
22	The second matter is this: outside the doors there's	22	Opening statement by STEVEN SNOWDEN
23	a small notice, perhaps a bit too small, which says,	23	MR SNOWDEN: Sir Brian, ladies and gentlemen, good morning.
24	"Please don't take photographs". It is the sort of	24	It is a pleasure to stand here and to be able to speak
25	notice you see outside many event halls and which you	25	to you and to address you on behalf of those that we
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1	see other people often ignoring and nothing seems to	1	represent.
2	happen. But there is a particular reason for it in	2	Let me explain who we are, as I begin. I am
3	these proceedings, which is that a number of those who	$\begin{vmatrix} 2\\ 3 \end{vmatrix}$	Steven Snowden, with my junior, Brian Cummins, we are
4	are here do not want their photographs to be taken and	4	instructed by Collins Solicitors. They are a law firm
5	certainly don't want them to be posted on the media	5	who have inevitably had to do significant amounts of
6	without their permission.	6	work pro bono on these issues, over many years.
7	Now, that happened overnight. I am sure that	7	Who are the people, who are those who I am
8	whoever took the photographs meant nothing by it,	8	privileged to represent today? Over 800 individuals of
9	nothing malign by it, and may simply have missed the	9	whom more than 650 are already Core Participants in this
10	notice. But could I just ask that no photographs are	10	Inquiry, a significant cohort of this Inquiry. It is
11	taken without the consent of the person being	11	expected, we expect, that more will be added as this
12	photographed. The hall has been designed so that and	12	Inquiry moves forward.
13	those in charge of it have been asked to recognise the	13	They are all ages, all backgrounds. They are a true
14	need to respect people's rights to privacy. So, that is	14	cross-section of society because the treatment disasters
15	the second element of rights.	15	with which this Inquiry is concerned do not
16	May I say that the press have been very, very good	16	discriminate.
17	about respecting privacy. For you will all have seen	17	They are those who are infected and those who are
18	that they don't take photographs of people without	18	affected. Amongst the group who instruct me there are
19	permission, and I thank them in particular for that. It	19	families, bereaved family members, partners, widows,
20	is so easy in a bit of news reel to pick up people whose	20	widowers, children, grandchildren.
20	faces are there, but who wouldn't want those faces to be	21	The majority of those who instruct us are
21	shown on the media without their permission.	21	haemophiliacs or the family and relatives of
23	The third matter, I mention it now, you will have	23	haemophiliacs, or those infected by intimates, as the
24	seen from the programme that this afternoon we have	24	expression has it.
25	people who will be expressing a different perspective on	25	There are also some who received whole blood
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1	transfusions and misdiagnosis, but our largest group of	1	enthusiastically welcome this Inquiry and intend to work
2	clients are those infected or affected by the	2	with it.
3	administration of factor concentrates.	3	We believe this Inquiry is a truly momentous
4	Those who have spoken before me have dwelt on the	4	opportunity to deal with matters of the utmost
5	horror of the symptoms and of the conditions, but we	5	significance. In one sense nationally and politically
6	represent those within those who instruct us a full	6	in terms of public accountability, in terms of our
7	spectrum of primary illnesses and diseases that this	7	collective conscience as a nation to recognise and
8	Inquiry will consider, all forms of Hepatitis viruses,	8	acknowledge where wrongs have occurred, and coming
9	HIV, CJD, and all of the life shattering complications	9	closer to home on a family and a personal level.
10	of those conditions on which others have already dwelt.	10	This is the first inquiry of this magnitude for this
11	In addition, as again others have already said and	11	many participants with the power to compel on a UK-wide
12	I know more than echo, there are the consequential	12	scale, to require documents to be produced, witnesses to
13	conditions; there is depression, there are cancers.	13	be called to account and, for those whose conduct has
14	Other lawyers have spoken to you about that, but you	14	been questioned, to have the opportunity or to be
15	yourselves have spoken far more clearly and far more	15	compelled to come forward and tell the truth. It is
16	eloquently in the video commemoration from this very	16	a very real opportunity to get the answers that people
17	stage and directly in conversations around this hall	17	have waited decades for, provided that it continues in
18	over the last 48-hours.	18	the spirit in which we are glad to say it has begun.
19	The language you have used, of the shadow hanging	19	The nature of the events under scrutiny stretches
20	over each infected person, is powerful and sobering.	20	language to describe, but as Professor Winston said,
21	Most of those I represent are members of one of seven	21	this is the biggest treatment disaster in the history of
22	campaign groups who have fought for decades and bring	22	the National Health Service. It is therefore the
23	much needed and much welcomed expertise to this Inquiry.	23	Inquiry which affects more individuals than any other in
24	Factor 8, The Birchgrove Group, The Fatherless	24	British legal history, I believe.
25	Generation, The Forgotten Few, Manor House,	25	Those I represent, and others in this hall, have
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1	Positive Women and Tainted Blood. It is our privilege	1	campaigned and waited for decades. They desperately
2	to act for them in their pursuit of justice. I'll come	2	hope it will serve its purpose of achieving justice.
3	back to that word in a moment.	3	That word again, we'll come back to that.
4	By way of preliminary comments though, Mr Chairman,	4	Secondly, we bear in mind this is a public inquiry
5	where we appear in the running order, after what was	5	of previously unseen magnitude and extent. So many
6	said and heard yesterday, what can we sensibly say or	6	victims past, present and future, such a period of time
7	add? We do endorse all of what was said to the Inquiry	7	to investigate the investigation not only of the
8	yesterday by the various individual and group infected	8	facts and the circumstances of infection, but of how
9	and affected Core Participants. I hope to avoid	9	individuals and their families were treated, medically
10	repetition this morning, but if I do, please take it as	10	and socially. Investigations of how their persistent
11	re-emphasis rather than repetition.	11	attempts to know, to understand and to obtain justice
12	I am confident in light of what's gone before that	12	have been rebuffed, have been pushed back and have been
13	I will be less than the full hour allocated to me and	13	covered up, we believe. Now is the time for that
14	I hope that will assist with your timetable for the rest	14	conduct to stop and for decency to prevail.
15	of the day.	15	Thirdly, we bear in mind this is an opening. It is
16	At the outset, I want to make four preliminary	16	the start, it is a beginning. We do not yet have the
17	comments.	17	documents or the evidence. There are many theories,
18	First, this is the third public inquiry in the	18	suspicions and concerns, none as yet tested or probed
19	United Kingdom. Archer, a private inquiry, no ability	19	forensically in public, and we are very grateful that
20	to compel witnesses. Penrose, in Scotland, in which	20	that opportunity is afforded us. We therefore tread
21	those infected and affected had no real voice.	21	lightly over some of the detail now, but rest assured we
22	Sir Brian, you must understand and we know that you	22	expect it to be scrutinised fully in the course of this
23	do the feeling from those I represent that they have	23	Inquiry. This is an opening statement, and we are
24	been here before and there is therefore some caution to	24	responsible enough to wait for evidence to be seen,
25	our enthusiasm. But we do say at the outset, we	25	heard and tested before reaching conclusions on it.
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1	Fourthly, we've already heard many personal stories	1	Those individuals feel disempowered. Their trust is
2	and personal accounts. We will hear more today. You	2	broken.
3	have seen some in the commemoration, some of you have	3	I would like to take us one stage further in the
4	spoken to the press. Many, Mr Chairman, we know, have	4	Hillsborough story than David Lock took us yesterday,
5	spoken directly to you. We recognise and are grateful	5	beyond the conclusion of the Inquest. The former Bishop
6	that the Inquiry has indeed taken the time and the care	6	of Liverpool, who I know many of you have met, The Right
7	to meet with individuals and to put them at the heart of	7	Reverend James Jones was commissioned in the wake of the
8	this Inquiry.	8	final Hillsborough Inquest by the Prime Minister, when
9	Let me tell you what I'm going to tell you over the	9	she was Home Secretary, to report on the experience of
10	next 20 minutes or so. What will I say in this opening?	10	the ordinary members of the public who were victims.
10	First of all, we welcome this opportunity at an early	11	His report, produced in November last year, is called
12	stage to have a voice heard and to engage in dialogue	12	forgive the language, but this is it:
		12	
13	about what matters to us with this Inquiry going		"The patronising disposition of unaccountable
14	forward.	14	power."
15	I will therefore say something about how the Inquiry	15	I would like to quote from two paragraphs from his
16	must go about its work, we suggest.	16	introductory letter. The Bishop writes:
17	Each and every single one of the terms of reference	17	"Over the last two decades, as I have listened to
18	is vital, but, Mr Chairman, we know you have invited our	18	what the families have endured, a phrase has formed in
19	thoughts on that, and we will emphasise a few and add	19	my mind to describe what they have come up against
20	some observations. I will conclude with some practical	20	whenever they have sought to challenge those in
21	and procedural comments, but I will follow the pattern	21	authority: the patronising disposition of unaccountable
22	set by others before me, who spoke yesterday, and leave	22	power. Those authorities have been both in the public
23	detailed submissions on certain areas to another	23	and in the private sector. The Hillsborough families
24	occasion.	24	[he recognises] are not the only ones who have suffered
25	Let me come back to the word I mentioned twice:	25	from the patronising disposition of unaccountable power.
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1	justice. Those I represent seek justice. It is easy to	1	The families know there are others who have found that
2	say that the purpose of this Inquiry is to achieve	2	when, in all innocence and with good conscience, they
3	justice.	3	have asked questions of those in authority on behalf of
4	What does that mean?	4	those they love the institution has closed ranks,
5	Those I represent have fought and fought and	5	refused to disclose information, used public money to
6	campaigned and asked and enquired and sought clarity and	6	defend its interests and acted in a way which was both
7	sought redress and demanded this Inquiry after doors	7	intimidating and oppressive."
8	were slammed in their faces, and their overwhelming	8	Pausing. Does that sound familiar?
9	common experience is of having been ignored, sidelined,	9	So, he carries on:
10	belittled by those in authority.	10	"The Hillsborough families struggled to gain justice
11	Without exception they are all individuals who	11	for the 96 has a vicarious quality to it, so that
12	placed their trust in medical professionals. This, of	12	whatever they can achieve in calling to account those in
13	course, was in the context of the 1970s and the 1980s	13	authority has a value to the whole nation."
13	and the prevailing view that doctors, like others in	14	That, we suggest, is very much the sense of what we
14	authority in those decades, were always right. We know	15	and you in this hall have been told time and time again
16	that is not the case. That was eloquently expanded	16	by those I represent. It has been their experience,
		17	
17	yesterday by David Lock QC in the context of	17	too. That we use another simple word for it is "wrong".
18	Hillsborough. If you recall, he talked to us about	18	When I say that, I don't mean a lawyer's textbook
19	that, where after years the families were eventually		,
20	proved right and the state was proved wrong and then	20	definition of a crime or of negligence, but in the mind
20	wrong and then wrong again, several times, until	21	of any right thinking person it is simply wrong that
21			
21 22	eventually justice prevailed.	22	that occurred. It should not have happened.
21 22 23	eventually justice prevailed. Those I represent, who placed their trust in medical	23	How do we define the justice that we, they, you
21 22 23 24	eventually justice prevailed. Those I represent, who placed their trust in medical professionals then placed their trust in government.	23 24	How do we define the justice that we, they, you seek?
21 22 23	eventually justice prevailed. Those I represent, who placed their trust in medical	23	How do we define the justice that we, they, you

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1	to the facts and information is the foundation of	1	"In the event of a public tragedy activate its
2	achieving justice in this Inquiry. Those I represent	2	emergency plan, deploy its resources to rescue victims
3	are demanding to know what actually happened, for	3	[but listen to this] to support the bereaved and to
4	individuals and on the wider stage in the medical, the	4	protect the vulnerable."
5	commercial and the political sphere I will come back	5	Let's pause and put that in our experience of what's
6	to that in a moment. What actually happened at the time	6	happened here.
7	when factor concentrates were introduced, when the alarm	7	In this context, we do question the activities of
8	bells ought to have rung, and what then happened or was	8	the so-called charitable trusts, the extent of their
9	covered up when they began to ask perfectly proper	9	support for the bereaved, the equality of their support
10	questions.	10	and their protection of the vulnerable.
11	We want to see and hear the truth, the unvarnished	11	Point two of the Bishop's six points:
12	full truth. We don't want redacted documents. We don't	12	"Public bodies should place the public interest
13	want privilege or public interest immunity to be	13	above their own reputation."
14	claimed, and we are grateful that you, Sir, don't want	14	Again, pause and apply that to our situation. Those
15	that either. But I'll mention in a moment how that	15	who I represent say, "Do not be defensive. Do not
16	device or those devices continue to be deployed, even	16	obstruct this process. Do not withhold documents, do
17	today.	17	not lie to us any more. Do not seek to mislead the
18	So, we need to know the full truth of what happened.	18	Chair of this Inquiry. Do not tamper with documents.
19	We then need to have what was done analysed to	19	Do not stall, do not be slow to comply. Volunteer, be
20	understand what ought to have happened instead, and to	20	proactive with documents, be proactive with witnesses
21	have that stated openly. There needs to be	21	for this Chair and this team. We, the infected and
22	accountability, there needs to be redress and there	22	affected, demand no less".
23	needs to be no way that this and by this we mean not	23	The Bishop's third point in his Charter, which he
24	only the initial infection, but what we do not hesitate	24	encourages public bodies to adopt, is this:
25	to call the cover-up which followed it can happen	25	"They should approach forms of public scrutiny,
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1	again.	1	including public inquiries and inquests, with candour in
2	Let me come back to The Right Reverend James Jones.	2	an open, honest and transparent way, making full
3	In November 2017, as I say, he published his report. He	3	disclosure of relevant documents, material and facts.
4 5	recommended a document to public bodies. That document is called:	5	[They endorse this sentence.], our objective is to assist the search for truth."
-	"The Charter for Families Bereaved through Public	6	Let me re-read that:
6 7	Tragedy."	7	"Our objective is to assist the search for truth."
8	And I pause to mention "bereaved" could equally be	8	We look to those public bodies and we say: can you
8 9	read as "infected" in this case.	9	say that is what you have done in the past? Can you
	Unfortunately, it is not clear to us whether the	10	undertake that that is now what you will proactively do?
10 11		10	This is not a witchhunt, but we do want you, the
	public bodies represented in this Inquiry have yet	12	public bodies, to view this as an opportunity to be
12	committed to that Charter, because this should not be an	12	
13 14	Inquiry dealing with bodies who are closing doors in our faces or holding them air only on their terms, but an	13	honest. The Bishop's fourth point:
14 15	faces or holding them ajar only on their terms, but an Inquiry with public bodies and government positively	14	"Avoid seeking to defend the indefensible, or
		16	dismiss or disparage those who may have suffered where
16 17	welcoming the opportunity to engage with us and with the Inquiry and to be frank. They should be welcoming it	17	we have fallen short."
17		18	Let's apply that to ourselves. We suggest they
18	genuinely, fully, far more than lip service.	10	should not stigmatise those innocent communities any
19 20	This is a public tragedy, in the sense Bishop James	20	longer.
20 21	was describing, and the things he says about the perspective of the bereaved and the injured must not be	20	Point five, the Bishop suggests:
21		21	"Public bodies should ensure all members of staff
22	lost.	22	treat members of the public and each other with respect
23 24	As I say, his Charter is a document which he	23	and courtesy. Where they fall short, they should
24 25	encourages public bodies to sign up to and to commit in	24	apologise straightforwardly and genuinely."
25	six points that they will do the following: point one:	2.5	aporogise suargituor wareny and genumery.
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1	We say, for this Inquiry, they must respect the	1	relieved to discover that she stood by him. But then,
2	entitlement of people to know. They must respect the	2	with her support, undergoing a repeat of that fear and
3	hide.	$\begin{vmatrix} 2\\ 3 \end{vmatrix}$	anguish in telling her parents before they married. As
4	The Bishop's sixth point:	4	an adult, applying for jobs, mentioning his diagnosis of
5	"Recognise that they are accountable and open to	5	haemophilia, but not the diagnoses of HIV or Hepatitis
6	challenge."	6	for fear of stigma and prejudice.
7	Being accountable is not an end in itself. It is	7	Now, in his 40s, he receives what for many would be
8	the first step in learning, in changing and in putting	8	the crippling blow of being diagnosed with cancer, but
9	right.	9	in his case, it was what he described as a strange
10	We draw those six points together and we say that	10	relief to realise that this was an illness he could
10	the time has now come for the defensive and	10	actually tell people about, not something he felt he had
12	self-exculpatory attitude of the public bodies to end.	12	to hide. Can we contemplate that? How has it come to
12	It cannot be right that those who are or were employed	12	that?
13	by the state in that sense to serve us all, to protect	14	These are the sorts of experiences the Inquiry must
15	their own interests.	15	understand and we know, Sir, that you try to do so, to
16	We do not know, as I say, whether any of those	16	fully comprehend what has been suffered. I emphasise
17	represented bodies who will speak after me, this	10	this is not limited to those with HIV/AIDS, those who
18	afternoon, have signed up to that Charter. If not, we	18	suffered other conditions, most notably Hepatitis, face
19	challenge them to do so.	19	stigma and abuse from its association with intravenous
20	May I turn to what I have put forward as how the	20	drug use and with alcohol.
20	Inquiry should go about its work, and I have called this	20	So, that is the time and the attitudes in their
22	"mindset" and "context".	22	context, I hope.
23	We suggest the Inquiry must bear in mind the time	23	Secondly, the complete innocence of those infected
23	and the attitudes. It must bear in mind, secondly, the	24	and affected. These are entirely innocent individuals
25	complete innocence of those infected and affected, and	25	whose trust in the state has been broken. It is
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1	it must look with scepticism at what I will call the	1	essential the Inquiry is full and fearless, and we and
2	"narrative of necessity". I will explain that in	2	all the other Core Participants represented today are
3	a moment.	3	determined to ensure that it will be.
4	But, first, to put the context the Inquiry should	4	These are not, as sometimes caricatured, grasping,
5	operate in, the time and the attitudes.	5	complaining claimants, seeking a financial lottery.
6	In order properly to understand the experience and	6	They are not a nuisance. They are not just a thorn in
7	the suffering of these individuals and families, the	7	the side of successive governments or the medical
8	Inquiry must consider the time and the social attitudes	8	profession. Their stories are horrific. Their
9	when this occurred. All those whose infection became	9	suffering is genuine. It was entirely avoidable and
10	public knowledge suffered huge stigma of the sort which	10	they have been ignored.
11	is almost impossible to conceive in the changed world,	11	They deserve the certainty of future peace of mind
12	in the changed social understanding we exist in today.	12	and dignity. Peace of mind for those infected, for
13	That stigma, of course, compounded their medical	13	those they love, for instance the mothers and fathers
14	suffering.	14	diagnosed, who have had to ask themselves, "What will
15	Forgive me if I tell you one story of a history	15	happen to my children?", for the wives and widows
16	relayed to us at this Inquiry by one of the Core	16	infected and affected, for their children who should
17	Participants I represent. His story is this: aged 3,	17	have been and the grief at their loss.
18	diagnosed as haemophiliac. Prescribed factor	18	Innocent.
19 20	concentrate. Diagnosed with Hepatitis C. Aged 16,	19	Thirdly, the "narrative of necessity", as
20	diagnosed with HIV. A vulnerable, troubled teenager	20	I described it. What do I mean by that?
21	believing his life was over, going off the rails.	21	That is the narrative sometimes put forward that
22	Pulled back, if I may use the expression, by the love of	22	factor concentrates were some form of necessary ground
23 24	a good woman. Aged 21, after nine months having to go	23 24	breaking treatment which simply had to be developed and
24 25	through with her the fear and anguish of having to tell her about his illness, frightened of what she would do,	24	deployed. We suggest that is simply untrue. Perhaps it was indeed put forward to its recipients as a wonder
23	ner about mis miness, mightened of what she would do,	23	was muccu put for ward to its recipients as a wonder
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1     drug, but those I represent consider the question of with the greates of respect. Mr Clairman at the connect to the Inpuiry, but not to use about your work.       3     risks and the risks of viral infection in blood hall long asked sufficiently clearly.       6     Who are perhaps more cumbersome the existing in harmophilia learnment of cryoprecipitate was effective and, importantly, significantly safer. If thid not have to be supersided then by factor concentrates. It was not inherently duagrous. It came from single donors, not form combinations of thissends, is Factor econorchitally.     10       14     We do not accept there was insufficient econorchitally, during the dual provide the resisting in effect commoditing budge products, and wak we to estable induce the existing and research of this fungity will establish conclusively - to bring with it lengity to available commoditing budge products, and wak we to ensider - and what we believe this lingity will establish conclusively - to bring with it negative to the other commoditing budge products, and wak we believe we that unit agoing to be some and protice last we that many and all transceable risk.       2     Others, systeriday, induction the karveledge. They website we believe with its group website sohono as so nome than an unbun myth that hather some concentuities with due of the argin type website to concentuities with d				
<ul> <li>risks and the risks of viral infection in blood Pad long</li> <li>risks and the risks of viral infection in blood Pad long</li> <li>risks and the risks of viral infection in blood Pad long</li> <li>risks and the risks of viral infection staked, or was not a sked, or was not a sked attickently clamy. In this question, is infecting the energy of the set of the concentration of the organization of the concentration of the organization of the risk is multiplied</li> <li>reconcentratis di, where the risk is multiplied</li> <li>exponentially.</li> <li>we have been increased if necessary. The shift from the organization or or hour the right conclusion from the streem the screem documents, in recessed if necessary. The shift from the organization or how the linguity shaft or organization or the streem the right conclusion from the streem the carry organization or the streem the streem organization.</li> <li>reconsider the organization organization organization or the organization organization or how the linguity shaft.</li> <li>reconsider the organization organization organization or the organization or how the linguity shaft.</li> <li>reconsider the reconstructs, in the organization organization or how the linguity shaft.</li> <li>reconstruction or how the linguity that entry?</li> <li>reconsthe the linguity that entry?</li> <li>reconsthe the linguit</li></ul>	1	drug, but those I represent consider the question of		
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Infected Blood Inquiry - Preliminary Hearing

1	Litigation in 1989/1990, and its settlement should be	1	"Your request is still being considered. We are
2	sought and disclosed as that clearly falls within the	2	sorry for the delay."
3	terms of reference.	3	He chased again for an update at the end of July.
4	Now, we understand the Department of Health have an	4	He received the same sort of apology in August. He
5	effective system of electronic filing, or at least	5	chased again in mid-August. Frustrated, he then changed
6 7	electronic cataloguing, which can be searched easily, but we do suggest that documents must also be sought	7	tack and, with commendable determination, put in a Freedom of Information request for all government
8	from the Treasury. We understand they have the same	8	emails discussing his previous request for those
8 9	effective system of electronic filing or cataloguing to	9	20 pages. He wanted to know what had gone on. In
10	allow relatively easy access. We would expect the	10	return, he received 30 pages of emails between the
10	Treasury to have documents relating to the financial	10	Treasury and The Cabinet Office discussing simply how to
11	implications and any cost benefit analysis, and that's	12	respond to his request for 20 pages of documents. But
12	important to know. That will be important to know.	13	those 30 pages of emails suggest that the 20 pages
13	We also suggest the documents must be sought from	14	should not be provide because they mention something
15	the Foreign Office for contact with US authorities and	15	a lot and that something, whether it is a name, whether
16	with overseas pharmaceutical companies. But, at	16	it is a process, whatever it may be is redacted from the
17	present, the Foreign Office tell us those of us who have	17	emails he has received.
18	enquired that they must search manually through paper	18	That illustrates, Mr Chairman, the difficulties that
19	files. Freedom of information requests are refused on	19	individuals face. We desperately hope that public
20	the basis that provision of the information would	20	bodies are more cooperative with the Inquiry than with
21	disproportionate, it costs them too much to do it.	21	individuals. But what are we to think of that? What is
22	We also respectfully suggest that documents must be	22	any fair-minded observer to think of that?
23	sought from The Cabinet Office, where we believe	23	Let me come briefly, on a micro or a personal level,
24	critical decisions were made in respect of, for	24	and give you more account, it may be the experience of
25	instance, the HIV litigation.	25	some of you sat in this hall. One of the Core
	Page 25		Page 27
1	Let me give one example of issues on the larger, the	1	Participants yesterday told us that his father, one of
2	macro, the bureaucratic scale. One of the Core	2	the infected, died when he was 11. His mother paid £240
3	Participants I represent asked, under Freedom of	3	for his medical records and received 600 pages in
4	Information, for lists of files, where certain key words	4	a file. He read through them and he recognised that
5	appear in their title. That is how one does it, many of	5	there were cross-references to other records, so this
6	you in this room will know.	6	set wasn't complete. So, he went back to the hospital
7	As a result, he obtained a full list of file titles	7	where it was indeed recognised that there was another
8	and the dates those files covered. He therefore became	8	file of 600 pages, but astonishingly, the hospital's
9	aware of the existence of a Treasury file not a	9	first reaction was to suggest that because he was not
10	Department of Health, but a Treasury file	10	his father, his dead father, he couldn't get those
11	dated December 1991 and entitled:	11	records.
12	"Health risks and special initiatives haemophiliacs	12	They releated on that, but then and this is
13	and acquired immunodeficiency syndrome."	13	important they would not relent from further payment
14	That, on the face of it, looks, doesn't it, as if it would be relevant to the issues? He asked for that full	14	for the additional records. He was told that there is
15 16	file. He received a response that he was not entitled.	15	a system for destruction for old records. Fortunately
16 17	*	16	for him, these were just about coming up for destruction
18	It would be too expensive to produce it, according to the test.	17	in November of this year, so if he could hang on a bit
18	So, then he changed tack and he asked just for the	18 19	and go back in November he could get them without having to pay the fee because they would otherwise just be
20	first 20 pages. How could that be disproportionately	20	destroyed.
20	expensive? That was in May 2018. He received	20	That, we respectfully suggest, is an utterly
22	a standard form acknowledgement from the Treasury.	21	unacceptable attitude and suggests that some trusts have
23	In June, he then pointed out the time for his	23	not understood or implemented the clear guidance issued
24	request to be complied with had expired. The response	23	by this Inquiry.
25	simply said:	25	So, that illustrates on a personal level how
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1	difficult it still is for individuals to obtain their	1	very important, of course as we know, in understanding
2	records even this month, when the Inquiry has started.	2	the issues of self-sufficiency. We suggest that the
3	There are still problems with trusts destroying	3	Inquiry and scrutiny of the roles of the Blood Products
4	individual's records, and we do encourage the Inquiry	4	Laboratory, at Elstree, the Plasma Fractionation
5	again and again to bring to the attention of health	5	Laboratory in Oxford and the Protein Fractionation
6	trusts what is expected of them.	6	Centre in Edinburgh is required. We know they were
7	May I turn to a third aspect of practical points for	7	unable to meet demand, and then commercial Factor
8	how we respectfully suggest the Inquiry should go about	8	concentrates began to be purchased from the USA, despite
9	its business; that is to do with commercial concerns.	9	risk.
10	As I observed a moment ago, counsel to the Inquiry	10	Self-sufficiency, of course, was raised as an
11	mentioned in her opening that documents are being sought	11	objective by David Owen, in 1974/75, but despite funding
12	from five pharmaceutical companies, unnamed. We note	12	being provided, it was still not achieved by its target
13	that none is represented today, so far as we know, nor	13	of 1977 or at all. The question is: why not?
14	to our knowledge is any Core Participant. She did not	14	The answer will in part lie, we suspect, with
15	name them. Their names, or at least the names under	15	material from the Blood Products Laboratory.
16	which as a matter of fact they traded and manufactured,	16	We know there was significant problems at the BPL in
17	or supplied factor concentrates in the 1970s or 1980s	17	the late 1970s and early 1980s. Expansion was pursued
18	are well known to those in this hall.	18	in 1981. It had a change of management and a change of
19	We express the hope that formal approaches from the	19	control to the NHS. Necessary increases to the UK
20	Inquiry will not attract what I can describe as a heavy	20	capacity was still not attained though. Products
21	handed response from successor companies to references	21	continued to be imported despite the known concerns.
22	private individuals make in the press or in the public	22	Criticism was made of its management, in a 1981 draft
23	to the roles they historically played. We desperately	23	paper, as being too diffuse, fragmented responsibility,
24	hope the Inquiry obtain their documents. It seems to us	24	insufficiently and not continuously coordinated. Those
25	imperative that their role is investigated and to the	25	responsible had very little experience of managing
	Page 29		Page 31
	0		0
1	utmost extent that the rules and the jurisdiction of	1	facilities of the kind concerned. The directors of the
1 2	this Inquiry will allow, bearing in mind that companies	1 2	facilities of the kind concerned. The directors of the laboratory are required to work out adequate policy
		1	
2	this Inquiry will allow, bearing in mind that companies change we know that as a matter of record. We urge this Inquiry to obtain and disclose all	2 3 4	laboratory are required to work out adequate policy guidance and without sufficient expert monitoring of their laboratory's performance.
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2 3 4	this Inquiry will allow, bearing in mind that companies change we know that as a matter of record. We urge this Inquiry to obtain and disclose all relevant documents it can from private and commercial concerns, to require evidence from witnesses who were in	2 3 4 5 6	laboratory are required to work out adequate policy guidance and without sufficient expert monitoring of their laboratory's performance. Shamefully, that paper was severely redacted by officials before submission to ministers. We want to
2 3 4 5 6 7	this Inquiry will allow, bearing in mind that companies change we know that as a matter of record. We urge this Inquiry to obtain and disclose all relevant documents it can from private and commercial concerns, to require evidence from witnesses who were in any role of significance in decision-making in those	2 3 4 5 6 7	laboratory are required to work out adequate policy guidance and without sufficient expert monitoring of their laboratory's performance. Shamefully, that paper was severely redacted by officials before submission to ministers. We want to know who did this and why, so we can understand how
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Infected Blood Inquiry - Preliminary Hearing

	1		
1	documents, so that they are as accurate as possible.	1	cap or budgetary limit or limit on hours, and we do
2	We do ask, though, whether it is right to have that	2	invite the Inquiry this is not an easy area, we
3	account for those not represented by lawyers given	3	recognise to consider it carefully. We appreciate
4	to an investigator for the Inquiry in a simple narrative	4	this is not a court case, there are no parties, so
5	form: sit down and tell me your story. That's where it	5	expressions like "parity of arms" are inappropriate. We
6	must start, but accounts must be cross-referenced to	6	absolutely recognise that, but we do suggest that it is
7	that individual's medical records or to the records of	7	fundamentally wrong in a public Inquiry of this
8	the relative who was infected. Recollection of dates	8	magnitude to put individual Core Participants in
9	and events of 30 years or more ago will inevitably be		a position where those representing them either have to down tools when the budget is reached, leave the work
10	uncertain and prone to error and, for this Inquiry, the	10	undone, the representations underprepared or act
11 12	timeline and the numbers are important, as will be	12	pro bono, when government body Core Participants do not
12	drawing inferences from many individual's medical records.	12	face those restrictions. There should be a level
13		13	playing field.
14	It may well be that trends will emerge from references in medical records to treatment decisions,	14	
15		15	I say that carefully. We are entirely in favour of
10	recommendations. In the main sphere in which I practice, of medical and personal injuries law, we	17	transparency over funding and resources, and we do hope to carry this conversation on with the Inquiry team over
17	know how difficult it is for even the most diligent and	18	the next days and weeks.
18	determined solicitor to obtain and piece together an	10	Let me turn briefly to the terms of reference. Some
20	individual's full medical records, especially in cases	20	additional points, some areas of emphasis. Those we
20	of complicated or multiple conditions, treated at	20	represent are clear in communicating to us, and inviting
21	different hospitals or clinics. So, we do suggest that,	21	us to communicate to you, that they welcome the detail
22	for those not represented by solicitors, thought should	22	of the terms of reference and they welcome the Inquiry
23	be given by the Inquiry to someone on the Inquiry team	23	into each and every aspect identified. This, therefore,
25	carefully cross-checking the completeness and the	25	is without reducing the emphasis on all the others,
25	carefully cross-enceking the completeness and the	25	is whilout reducing the emphasis on an the others,
	Page 33		Page 35
1	accuracy of each individual's records as obtained and	1	I mention only a few.
2	pursuing any omissions quickly and thoroughly.	2	To us, the key issues of initial infection seem
3	May I turn for a moment to talk about resources,	3	simple. What's in your terms of reference as 1(c), what
4	fairness and parity of representation. This is not just	4	was or ought to have been known of the risks. 1(h), why
5	a moan. We have a real concern about resources. As has	5	were people given and how did they come to be given
6	been said by others who stood before me: as lawyers, we	6	infected factor concentrates. Issues 9(a) and 9(b)
7	do not see this Inquiry as an income generating	7	then, the issues of cover-up, and then that leads
8	exercise.	8	logically to issue 8, including the terms of the
9	On the contrary, as others have said, significant	9	litigation settlement, about how a civilised society
10	amounts of work have been undertaken by pro bono, which	10	should react to those events.
11	is a delightful lawyers' expression meaning for free or	11	Under paragraph 5 of the terms of reference, we
12	for good. I gratefully adopt what was said by	12	welcome the Inquiry into tissue samples being kept, sent
13	Mr O'Neill QC for the Scottish Core Participants, about	13	or tested without consent. Particularly, the testing of
14	Core Participants consciously limiting their role and	14	previously untreated patients, PUPs is the acronym,
15	their attendance and their representation to the issues	15	unnecessarily as guinea pigs. Those are both going to
16	that directly concern them.	16	be detailed historical document intensive areas and we
17	But I do and must mention only this: the fact that	17	welcome them as areas of Inquiry.
18	the infected and affected Core Participants are	18	We have already mentioned the role of the Blood
19	receiving public funds leads by a budget or a cap or	19	Products Laboratory to be considered and we suggest it's
20	rates and hours to an inevitable restriction on their	20	failure to recall batches for heat treatment when others
21	representation. That is true whether it is considered	21	were already doing so explored to a limited extent in
22		22	previous Inquiries clearly warrants attention and we
	that cap is fair or not. I pause to observe that the	1	
23	government bodies who are also Core Participants in this	23	think this falls under 1(h) and 1(i).
23 24	government bodies who are also Core Participants in this Inquiry are in truth also spending public funds on their	23 24	Commercial influence. We are pleased to see that
23	government bodies who are also Core Participants in this	23	

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Infected Blood Inquiry - Preliminary Hearing

1	and 1(h). We believe this is a key issue not adequately	1	acted illegally and continues to do so, as a credit
2	considered before.	2	broker taking equity release charges over people's
3	We venture to suggest another one, correcting or	3	properties and there are, we are told, significant
4	reopening inquest verdicts. This may fall under terms	4	problems and ongoing problems with the new statutory
5	of reference 9. This is one area where the proper and	5	body.
6	accurate recognition of someone's passing, their cause	6	At present, we understand from the possible timeline
7	of death, might assist with the sense of closure and	7	outlined by counsel to the Inquiry that hearings
8	recognition of what happened and resolution for those	8	inquiring into those terms of reference, that is the
9	left behind.	9	provision and the trusts, may not start until Easter
10	The death certificates of many who die of HIV/AIDS	10	2020. If so, we may not arrive at recommendations for
11	do not say so. They often refer to pneumonia as the	11	change, even by way of interim recommendations, until
12	primary cause of death. They almost never refer to	12	the latter part of 2020, two years hence. That we,
13	Factor products.	13	suggest, is too far away. This is one aspect of the
14	You have heard others endorse the view that doctors	14	Inquiry which we think could be extracted and expedited
15	were keen to play down the role of contaminated Factor	15	as far as possible.
16	concentrates. Death certificates often refer to	16	If, for instance, the issues of immediate need,
17	cirrhosis, rather than Hepatitis. So, we suggest that	17	eligibility and appropriate levels of support were taken
18	as this area is explored the Inquiry could usefully	18	out from the consideration of the historical position,
19	work, perhaps, with the chief coroner, to give guidance	19	without for one moment belittling the need to
20	for the future and guidance, if appropriate, for the	20	investigate what the trusts have done, it should be
21	re-opening or revising of past inquest conclusions.	21	possible, we would suggest, perhaps with the benefit of
22	Under terms of reference 9, a very significant	22	limited oral evidence, perhaps with written
23	concern of those we represent is the extent to which	23	representations, to make early recommendations about
24	they are now driven to depend on the State for their	24	changes to the level of financial provision. We commend
25	financial subsistence. They talk heartbreakingly about	25	that course to the Inquiry.
	D 27		D
	Page 37		Page 39
1	the indignity and the shame of having to apply to	1	Finally, a few practical procedural points. Fully
2	rejustify entitlement and, in effect, beg for charity.	2	electronic disclosure, we welcome that. That is the
2 3	rejustify entitlement and, in effect, beg for charity. Those concerns were eloquently put in the commemoration	2 3	electronic disclosure, we welcome that. That is the only way this Inquiry will work properly. Mr Stein QC
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Infected Blood Inquiry - Preliminary Hearing

1	express our provisional support, but that is already in	1	matched by the Inquiry. These have been an emotional
2	motion. We know that experts are beginning to be	2	sombre few days, but we can build on this, moving
3	appointed provisionally, we hear that at the end of last	3	forward.
4	week. We look forward to working with the Inquiry and	4	Finally, I am going to close by returning to the
5	other Core Participants on that, but we have had almost	5	report of Bishop Jones. I will take the liberty of
6	no time to consider names already promulgated.	6	adopting and adapting what he said at the end of his
7	It may be and I say this with great caution	7	introduction. He said this:
8	that there are some concerns to be raised over some	8	"People talk too loosely about closure. They fail
9	names identified already. It is right to say no more	9	to recognise there can be no closure to love, nor should
10	publicly at this stage, nor to go into specifics, but we	10	there be for someone you have loved and lost. Grief is
11	will liaise with other interested parties, other Core	11	a journey without a destination. The bereaved [and in
12	Participants and liaise with the Inquiry as soon as	12	this context we expand that to include the infected and
13	possible.	13	affected] travel through a landscape of memories and
14	Let me finish you may be grateful I am going to	14	thoughts of what might have been. It is a journey
15	finish let me finish by summing-up what we have said.	15	marked by milestones; some you seek, some you stumble
16	We have optimism, but we hope you understand it is	16	on. For the families and survivors of this tragedy,
17	cautious optimism for the Inquiry. We are determined to	17	those milestones do include the search for truth,
18	work constructively with you and your team.	18	accountability and justice."
19	We described what we mean when we say we seek	19	And we look to the Inquiry to provide those.
20	justice from this Inquiry. We challenge the public	20	SIR BRIAN LANGSTAFF: Thank you very much, Mr Snowden. We
21	bodies which are Core Participants to comply with The	21	now have Caz Challis, please.
22	Right Reverend Jones's Hillsborough Charter. We have	22	Opening statement by CAZ CHALLIS
23	suggested the mindset the Inquiry should adopt, to	23	MS CHALLIS: Good morning everyone, Sir Brian.
24	remember the context of the 1970s and 1980s, to	24	I am sorry we all have reason to be here, but
25	debunk if I may use that expression the	25	goodness, I have met some amazing people here over the
	Page 41		Page 43
1	caricaturing of those infected and affected, to debunk	1	last few days.
2	the narrative that Factor of concentrates hadn't been	2	First of all, I'd like to say how relieved I am that
3	necessary treatment. We have, I hope, made some	3	this Inquiry is finally underway. It has been such
4	practical suggestions of how the Inquiry might go about	4	a long time coming and sadly, as we know, it's come too
5	its work and emphasise some of the terms of reference.	5	late for many people. I hope it will uncover the truth
6	Will you forgive me if I share one more story, so	6	of what happened and will bring justice and some degree
7	that you may see the resilience of some of those we now	7	of closure to all those who have lost loved ones, and to
8	represent?	8	all those of us who are still here dealing with the life
9	I stress this is a true story and my junior counsel	9	changing effects of contaminated blood.
10	has insisted I share it. A Core Participant spoke to	10	I'd like to thank Sir Brian and the Inquiry team for
11	him yesterday. He was diagnosed with Hepatitis. He was	11	their good work so far, in making sure that we are
12	placed on medical treatments, which included pigs' blood	12	finally heard and for handing us the talking stick.
13	and Chinese cats' ovaries. Those are new treatments to	13	The terms of reference seem to be comprehensive and
14	me.	14	inclusive of everyone affected and what we had asked
15	He attended his consultant, who sadly told him he	15	for. The Inquiry team have come across as approachable,
16	may also have variant CJD. He said to his doctor, "I'm	16	compassionate and responsive to our needs as a whole
10	on pig's blood, cats' ovaries and now you are saying	17	community.
18	I may have mad cow's disease", he said, "Yes, I am	18	From what I've understood so far, this Inquiry team
19	afraid that's right". With resilience he responded, "Is	19	are determined to get to the bottom of this terrible
20	it a doctor I need or a vet?"	20	scandal that has taken and ruined so many lives, and
20	I haven't made that up. That is not me. That is	20	this will of course be the main focus of the
21	one of you, and only people who have been touched by	21	investigation.
22	sadness and tragedy could display that sense of humour.	22	I appreciate that this process of searching for the
23	The dignity, perseverance and dogged commitment of	23	truth and justice needs to be thorough, but given how
24	those in this hall to getting to the truth must be	25	much time has been lost already, I hope that it will be
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	9		~

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Infected Blood Inquiry - Preliminary Hearing

1	as efficient and fast moving as possible.	1	leniency regarding the harsh and arbitrary cut-off
2	My personal interest in the Inquiry is twofold.	2	dates, I was refused again.
3	I am here as a person who was infected with Hepatitis C	3	I am far more upset about this than I am about the
4	through NHS treatment, and I'm also here because of my	4	fact that I was accidentally infected.
5	voluntary work in Hepatitis C advocacy and my desire to	5	So, one of the things that I would like to see this
6	support others affected by contaminated blood.	6	Inquiry focus on is the examination of the various
7	I am here with a righteous anger for all those who	7	schemes' criteria to make sure that they are inclusive
8	are infected with HIV, Hepatitis B, Hepatitis C and	8	of all infected and that they don't discriminate against
9	other blood borne viruses when the blood products and	9	those of us who were infected in healthcare settings
10	treatments they were given were known to be risky.	10	through negligence, or accidentally, especially after
10	We need justice for the haemophiliacs who received	11	they began screening blood in September 1991.
11	infected blood products and for all those people who	12	I'd like the Inquiry to consider whether we need
12	received infected blood transfusions, anti-D and other	12	more education and awareness regarding the prevention of
		13	
14	blood products. I hope this Inquiry will expose any	14	transmission, both in the community and in medical and
15	cover-ups that occurred which we know they did and		clinical settings, so that accidents don't happen.
16	will help all of those affected, many of whom lack	16	In my case, Hepatitis C slipped through the net
17	medical evidence as a result of these cover-ups, to be	17	a few months after they began screening. I know there
18	heard.	18	will be many others in my situation who have been
19	My personal focus is on Hepatitis C simply because	19	infected post-September 1991, who either don't know and
20	that is what I know. I was infected with Hepatitis C	20	who consequently cannot get any acknowledgement or
21	myself through cancer interventions, which included	21	financial and emotional support.
22	a blood transfusion in early 1992. I want to stress	22	As a result of my own intensive study of Hepatitis C
23	that I am very grateful to my brilliant medical team for	23	during my search for knowledge, support and treatment,
24	saving my life several times over, and I direct no blame	24	I now work voluntarily on Hepatitis C advocacy, mainly
25	towards any of them. Their care was the very best.	25	in a large international online peer support group.
	Page 45		Page 47
	1 420 10		1 uge 17
1	However, as a result of the cancer and the	1	I interact daily with sick people struggling to get the
2	subsequent infection with Hepatitis C, my life over the	2	same information, support and treatment for themselves.
3	last 26 years has not been an easy ride.	3	So, I am here also as a campaigner for change in how
4	I was cured of Hepatitis C by taking part in the	4	we deal with Hepatitis C. Therefore, I would like this
5	clinical trial of Epclusa in 2015, but by then I had	5	Inquiry to consider the current state of Hepatitis C
6	already lost my quality of life and most of my working	6	care in the UK and to consider how it might be improved
7	years, including my career as a therapeutic counsellor,	7	upon, so that we can raise awareness, reduce stigma and
8	and I have never had any acknowledgement or support for	8	get people tested and treated quickly.
9	my loss of earnings and pension.	9	We know the look back exercise was woefully
10	I still have chronic fatigue. I have been	10	inadequate, and we know that people are still finding
10	humiliated time and time again, like many others, having	11	out that they were infected with contaminated blood
12	to jump through hoops at work capability assessments,	12	decades after the event, causing extreme trauma and
12	trying to prove that I simply cannot work due to the	13	meaning that many find out they have Hepatitis C when it
13	chronic fatigue and other long-term effects of my	14	is already too late to save them from complications and
14	illness and treatments, even though I may look fine.	14	liver damage.
16	This awful treatment of sick people needs to change	16	We also know that there are thousands of people out
10			there, far more than the official estimates, who will
18	for all those attected and I would like the Induiry to	1 17	
	for all those affected and I would like the Inquiry to look at this issue	17	
	look at this issue.	18	never find out until it's too late for them. I would
19	look at this issue. I have never received any financial help from the	18 19	never find out until it's too late for them. I would like to see the NHS testing every single person for
19 20	look at this issue. I have never received any financial help from the Skipton Fund or any other schemes, such as the English	18 19 20	never find out until it's too late for them. I would like to see the NHS testing every single person for Hepatitis C it is not an expensive test and then
19 20 21	look at this issue. I have never received any financial help from the Skipton Fund or any other schemes, such as the English Infected Blood Support Scheme, because I did not meet	18 19 20 21	never find out until it's too late for them. I would like to see the NHS testing every single person for Hepatitis C it is not an expensive test and then quickly treating those who test positive. This is the
19 20 21 22	look at this issue. I have never received any financial help from the Skipton Fund or any other schemes, such as the English Infected Blood Support Scheme, because I did not meet their strict criteria regarding dates of infection. My	18 19 20 21 22	never find out until it's too late for them. I would like to see the NHS testing every single person for Hepatitis C it is not an expensive test and then quickly treating those who test positive. This is the only way we will find them all.
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Infected Blood Inquiry - Preliminary Hearing

1	I personally know of some people who were given the	1	integrity and no little courage to come to me, seek me
2	older, cheaper, harsher Interferon and Ribavirin	2	out and tell me that and to ask me to tell you, which
3	treatments as they were not deemed "sick enough" to	3	I would just like to recognise.
4	merit the newer, very expensive ones.	4	He says he meant no harm at all. As I had
5	The government has pledged to eliminate Hepatitis C	5	anticipated, it was entirely one of those things, which
6	by 2025, but that will never happen unless everyone	6	understandably, perhaps, people wanted to have a memento
7	affected is found, diagnosed and treated quickly.	7	of being here.
8	However, drug pricing, currently, is prohibitive.	8	We now have the privilege of listening to Peter
9	So, perhaps ways must be found either to persuade drug	9	Burney, an unrepresented Core Participant.
10	companies to lower their prices or for the much, much	10	Opening statement by PETER BURNEY
11	cheaper generic equivalent medicines, which work	11	MR BURNEY: I would like to offer my sincere condolences to
12	perfectly well, to be purchased by the NHS.	12	all the families who have lost a loved one to this
13	I hope this Inquiry will consider what	13	tragedy. It must have been an absolutely horrific
14	recommendations should be made in order for the tens of	14	position to find yourselves in, to watch someone pass,
15	thousands of the unfound to be found, tested and	15	through no fault of their own, especially as it was
16	treated.	16	entirely through the negligence of others.
17	There is a serious lack of education and awareness	17	In a country as strong as ours, who condemn the rest
18	in the UK about Hepatitis C. Most lay people have never	18	of world if they infringe on the human rights of their
19	heard of it. If they have heard of it, it is likely	19	citizens and take the moral high ground at every
20	they will have preconceptions about how it might be	20	opportunity, whilst they themselves can stand by and
21	caught. Therefore, many people with Hepatitis C feel	21	watch the impact that this contaminated blood tragedy
22	marginalised and afraid to speak out.	22	has had on their citizens. That, to me, just takes the
23	I'd like this Inquiry to consider the role of	23	"great" out of Great Britain. One apology and ex gratia
24	education in reducing the fear and stigma associated	24	payments, papers going missing, medical records being
25	with Hepatitis C, and we have heard a lot about the	25	lost, politicians describing this as a cover-up "on an
	Page 49		Page 51
	1 age +7		1 age 51
1	stigma this morning, and to address the need for better	1	industrial scale" and threatening to go to the police.
2	practical and emotional support systems for those	2	Two sets of health secretary files have vanished into
3	affected.	3	thin air. This reads like a fictional Russian spy
4	So, finally, this government should look back,	4	novel, but this is happening in our country. A country
5	accept accountability and make amends to those affected	5	that our grandparents died fighting for and a country
6	by contaminated blood, as far as they are able. It	6	they fought for is standing by and watching their
7	should also look forward to ensure that this preventable	7	descendants die and have watched them die for decades,
8	disease is understood, identified, treated and finally	8	many of them victims, dying in poverty, leaving their
9	eliminated in the UK.	9	loved ones to have to depend on benefits and handouts
10	The lack of integrity shown by the government is in	10	and their deaths covered up by governments, who put
11	stark contrast to the tangible integrity in this room.	11	money before life.
12	I hope this Inquiry's investigations will provide the	12	All I can say is: shame on you.
13	framework and guidance for the work that lies ahead.	13	When the truth comes out which it will, history
14	Thank you.	14	will not treat you kindly.
15	SIR BRIAN LANGSTAFF: We will now take a 20 minute break	15	I know almost every one of us, infected and
16	until 11.35.	16	affected, are really angry at the way we have been
17	(11.15 am)	17	treated by previous governments and this government,
18	(A short break)	18	especially with the way this tragedy has not been
19	(11.35 am)	19	recognised for a lot of its victims. Where stigma has
20	SIR BRIAN LANGSTAFF: Can I say that, during the break,	20	been attached, forcing victims to have to suffer in
21	somebody came up to me who had been responsible for	21	silence, afraid of what may happen if people found out
22	posting the photographs, taking the photographs	22	they had a virus, and when it was discovered they had
23	vesterday, which I spoke about this morning. He wants	23	a virus, they have had to move home because of hate
24	through me to apologise to all of you who have been	24	slogans painted on their houses, their children bullied
25	upset by his doing so. It was, to my mind, an act of	25	at school. Victims have lost their jobs, relationship
1			
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1	break ups, then abused by the benefit system, which is	1	by any other motive other than getting to the truth.
2	still going on today.	2	From my experience with them they were courteous,
3	All this is because of the labels that have been	3	professional, sympathetic and they were very experienced
4	stuck on the various conditions by the government whilst	4	in what they do, and they were very, very thorough.
5	trying to cover-up what is most likely the worst scandal	5	But what really grabbed my attention was when
6	that modern day UK has ever been involved in. They	6	I found the team was training up experienced lawyers to
7	purposely ostracised us from the rest of society because	7	take our statements. I believe the Inquiry team will be
8	of the diseases they gave us when we trusted a system	8	taking statements across the UK, where people can go to
9	that was introduced to help us.	9	them, though I think a lot of it will be London based.
10	Who in their right mind would admit to being	10	I realised a lot of people may be reluctant to go public
11	infected with some of these conditions?	11	on this for various reasons. That should not be
12	I personally misled friends, family and neighbours.	12	a problem, as the Inquiry team have what they call
13	That is something I deeply regret, as in a way that	13	a "rapporteur", whose job is to take statements form
14	means I am lacking moral fibre.	14	various infected and affected victims. The rapporteur
15	Hopefully, the public will get a glimpse of what we	15	will go through statements and make a report, which will
16	have had to suffer for decades. For that's all it will	16	be handed to the Inquiry team. He will identify any
17	be, a glimpse. The public will never see the true pain	17	themes that become apparent to him. The Inquiry team
18	and anguish that we and our loved ones have had to	18	will go through his report and, once again, they will be
19	suffer. The governments knew there were tens of	19	looking for themes or anything that may help them
20	thousands of victims dying out there, yet it was cheaper	20	identify this cover-up. So, again, the more detail the
21	for them to let the virus run its course and watch us	21	better.
22	die. Each and every victim that passed was a victory to	22	If you don't want to be identified, the rapporteur
23	them because they said he had died as a result of	23	is an option you could use. We really do need to try
24	alcohol abuse or liver cancer, medical staff kept in the	24	and help ourselves as much as we can.
25	dark about conditions, Hepatitis not mentioned on death	25	No one will be as passionate about your story as
	D 50		7. 55
	Page 53	<u> </u>	Page 55
1	certificates. Hopefully it will all be exposed. What	1	YOU.
1 2	certificates. Hopefully it will all be exposed. What we need is justice for ourselves and the victims'	1 2	you. There will be some people who feel a sense of relief
2	certificates. Hopefully it will all be exposed. What we need is justice for ourselves and the victims' families who have lost a loved one.	2	There will be some people who feel a sense of relief
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1	"Decourse if a liver come up that weekend I would not	1	haing rafused we adopted a commonscense approach
1	"Because if a liver came up that weekend I would not	$\begin{vmatrix} 1\\ 2 \end{vmatrix}$	being refused, we adopted a commonsense approach.
2	survive the procedure".	$\begin{vmatrix} 2\\ 3 \end{vmatrix}$	Though there was no medical evidence, as it had been
3 4	I had end stage liver disease, hepatic	4	destroyed, we explored a different avenue. We obtained
5	encephalopathy and I was in a terrible condition. Thankfully, I am now Hepatitis C clear.	5	irrefutable evidence and, after answering a few questions from the professors on the Skipton panel, both
6	The reason I am telling you this is, if I would have	6	lump sum payments and annual payments were given.
7	been tested or made aware of this contaminated blood	7	What intrigues me is why was this approach not used
8	tragedy, my condition would not have progressed to this	8	by the Skipton. We think it is because the Skipton
9	stage; a few simple lifestyle changes would have saved	9	wanted to keep the number of beneficiaries as low as
10	me a lot of pain and my family a lot of anguish.	10	possible, to try to hide the enormity of the scandal,
10	We have, at this moment, a wonderful opportunity to	11	and to try and minimise the financial impact on the
12	raise awareness of Hepatitis B and C. Out of the	12	Department of Health.
13	325 million people living with viral Hepatitis globally,	13	In my opinion, that makes them complicit in this
14	upwards of 290, that is 9 in 10, are living with	14	cover-up.
15	Hepatitis without knowing it. We need to encourage	15	We have no desire to steal any limelight from the
16	people to come forward and get tested with the	16	Inquiry, but while we are raising the profile of the
17	availability of effective vaccines and treatments for	17	contaminated blood Inquiry, we can reach out to people
18	Hep B and a cure for Hepatitis C, the elimination of	18	in a kind of "get tested" campaign or Hepatitis
19	viral Hepatitis is achievable.	19	awareness. We can give the government a chance to put
20	If you were asked: have you ever had a blood	20	right a wrong. They should have followed other
21	transfusion prior to 1992? You automatically think of	21	countries' leads like France, Canada and made an effort
22	a red bag of blood. That is not the only thing you need	22	to find victims through advertising campaigns and
23	to be thinking about. You can become infected by	23	contacting previously transfused patients. I know there
24	platelets, immunoglobulin, Factor 8s and many other	24	was a half-hearted advertising campaign with dubious
25	pooled products. Also, people who have received	25	stigma-attached posters, just like a half-hearted look
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	i age 57		1 420 57
1	operations, such as C section births, dialysis, heart	1	back campaign, where there was another script the GPs
2	transplants or involved in any kind of trauma. In fact	2	had to follow to not give patients Hepatitis blood tests
3	any kind of surgery prior to 1992.	3	or HIV.
4	The problem is, in a lot of cases, you were	4	So, it must have been difficult for them, at that
5	unconscious and probably unaware that you were being	5	time, when their main aim was, at that stage, to
6	given contaminated blood products. So, anyone out there	6	cover-up a massive contaminated blood scandal. This
7	with unexplained liver problems, cirrhosis, and the	7	government may say: we can't put right the wrongs from
8	doctors may be saying, "Well, it is because you drank in	8	previous governments. We have given more to the
9	excess in your youth", you should be looking at getting	9	contaminated blood victims, and let's not forget the
10	tested. Just try and be assertive as you can and demand	10	apology.
11	a test. It could cost you your life.	11	They can make a massive difference now. Hepatitis
12	The main bug bear for me is new born children. Many	12	can be beaten now with vaccines and it will be
13	were given blood at birth and there is no way that they would know that, and birth records are quite often	13	cost-effective to treat it now before sufferers get to
14 15	destroyed. These children were born in the 1950s,	14 15	the transplant stage. The Department of Health should make doctors offer
15	•	15	the test, and even more so to people who have settled
10	1960s, 1970, so by now they should be showing signs of	10	here from other countries where Hepatitis is more
17			
10	the virus. I am the chairperson of a liver support group at Manchester Royal Infirmary, where we have found	1	1
19	group at Manchester Royal Infirmary, where we have found	18	prevalent. The UK was one of the last countries in the
19 20	group at Manchester Royal Infirmary, where we have found victims who have been transfused at birth and obtained	18 19	prevalent. The UK was one of the last countries in the western world to introduce the test for Hep C. And
20	group at Manchester Royal Infirmary, where we have found victims who have been transfused at birth and obtained payments from the Skipton Fund for them by using their	18 19 20	prevalent. The UK was one of the last countries in the western world to introduce the test for Hep C. And remember, I believe that there are still a lot of
20 21	group at Manchester Royal Infirmary, where we have found victims who have been transfused at birth and obtained payments from the Skipton Fund for them by using their parents' medical records and blood groups and birth	18 19 20 21	prevalent. The UK was one of the last countries in the western world to introduce the test for Hep C. And remember, I believe that there are still a lot of victims out there who have been given contaminated blood
20 21 22	group at Manchester Royal Infirmary, where we have found victims who have been transfused at birth and obtained payments from the Skipton Fund for them by using their parents' medical records and blood groups and birth certificates of infected children. These victims had	18 19 20 21 22	prevalent. The UK was one of the last countries in the western world to introduce the test for Hep C. And remember, I believe that there are still a lot of victims out there who have been given contaminated blood products. Yes, they know they are ill, but they can't
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20 21 22 23 24	group at Manchester Royal Infirmary, where we have found victims who have been transfused at birth and obtained payments from the Skipton Fund for them by using their parents' medical records and blood groups and birth certificates of infected children. These victims had previously been refused funding by the Skipton. Now, the reason I say this is we are not learned	18 19 20 21 22 23 24	prevalent. The UK was one of the last countries in the western world to introduce the test for Hep C. And remember, I believe that there are still a lot of victims out there who have been given contaminated blood products. Yes, they know they are ill, but they can't understand why. All we need to do is find them, and if we identify or save just one life, then this Inquiry has

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Infected Blood Inquiry - Preliminary Hearing

1	Another thing that bothers me is that the public may	1	Inquiry started. Well, the more time spent on
2	be led to believe that the cost of this Inquiry, or any	2	preparation may mean the less time spent on the actual
3	other litigation that follows the outcome of the	3	Inquiry, and failing to prepare is preparing to fail.
4	Inquiry, will come out of the NHS budget. We think it	4	I guess what I'm trying to say is: be patient, stay
5	should be made clear that this is a problem that	5	strong, and above all else try and keep well.
6	squarely lies on the shoulders of the government and it	6	SIR BRIAN LANGSTAFF: The next two statements to the Inquiry
7	will not affect the NHS budget in any way. This message	7	by individual Core Participants are going to be read to
8	should come from the government sooner rather than	8	you. That is their wish and we are making sure that
9	later. We have been stigmatised enough.	9	their wish is heard.
10	I am aware that other people wish to talk to you, so	10	Sarah Fraser Butlin, junior counsel to the Inquiry,
11	I will make way for them, but before I go I just want to	11	will read the statement, first, of Andrew Bragg.
12	make one more point, especially to the victims who are	12	Opening statement of ANDREW BRAGG (read)
13	watching from home, who can't attend today's meeting.	13	MS FRASER BUTLIN: Thank you, Sir Brian.
14	This Inquiry, though welcomed by everyone within our	14	The first statement I am going to read is
15	community, will have a daunting effect on many of us,	15	a statement on behalf of Andrew Bragg, an unrepresented
16	especially for those who are not able to be involved as	16	Core Participant. He says this:
17	much as they would like because of health problems or	17	"Due to work commitments I am unfortunately unable
18	personal problems, or both. Try not to let this Inquiry	18	-
19	take over your life or add to your anxiety levels.	18	to attend the preliminary hearings in person. I would wish to make the following statements regarding topics
20	There are people out there from within our community who	20	which, from my experience, I would propose to be
20	are more than capable of trying to get us all justice	20	
21	and are able to give evidence. Participate if you can	21	included within the scope of this investigation.
22	by telling your story, because the Inquiry is very much	22	"Firstly, understanding potential infection risks from blood and blood products. The Inquiry should
23	a victim-based Inquiry. You will be contributing more	23	
24 25	than you may know.	24	include an assessment of what systems and practices were
25	ulan you may know.	25	in place within government and the NHS from 1970, to
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1	I know social media sites may feel like a great	1	assess the potential for the infection from blood
2	source of information, but try not to believe everything	2	transfusion and blood products. This should include to
3	you read as often comments are made from an individual's	3	what extent information was gathered across the UK and
4	personal perspective, which may not represent what is	4	also from other governments, research organisations and
5	actually taking place. There always seems to be	5	any other interested parties.
6	difference of opinion in these sites, try not to get	6	"Having gathered such information, how was this
7	involved, as these kind of confrontations always seem to	7	communicated within the NHS and government, and how was
8	take you to a bad place.	8	it acted on?
9	Just try and respect other people's views, whether	9	"Secondly, the use of risk assessment and action
10	you agree with them or not, and don't try to force your	10	
10			identified. Organisations must use robust risk
	views on them. People will keep referring to the	11	assessment mechanisms to identify and respond to issues
12 13	Penrose and the Archer Inquiries for comparisons. All of it will be negative, but much was learnt from these	12	which may materially affect either the organisation or
	inquiries, both by us and the present Inquiry team, so	13	those it may have an impact on. It is clear that
14	hopefully we may be able to avoid some of the pitfalls.	14	concerns about potential infectious agents in blood and
15 16		15	blood products were in the public domain long before the
16	Those of you with legal representation should be	16	NHS took effective action. It is therefore important to
17	kept in the picture by your solicitors. If you have	17	understand what processes were in place to collect
18	a question for them, try emailing them, then at least	18	information and assess risks. What were the mechanisms
19 20	you will have a reply on an email. You may need it for	19	and systems in place to assess and act on potential
20	reference in the future.	20	risks identified with blood products and their use
21	Well, thank you for listening to all I've had to	21	within the NHS? How were risks quantified and potential
22	say, and hopefully this Inquiry won't take too long, as	22	consequences and recommendations communicated? How were
23 24	I know there are a lot of us out there who don't have	23	risks that were identified then acted on? What were the
24 25	a certainty or luxury of time.	24	organisational systems and roles charged with acting on
25	People may think that it's taken time to get this	25	such information? And what were the individual
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1     responsibilities of those controlling these actions?     1     referst.       2     "Thirdly, the score of optential exposure to HCV,     1     indistry in which l work, we operate in the full       3     Indiany of infections genit. If would appear there     3     indiany in which l work, we operate in the full       4     Intervisions and blood products, and to then take action     5     individuals may be held to be personally responsible.       7     to respond effectively. Some questions which should be     7     will be held corparately responsible.       10     these influences agents had been established how was     10     This responsible for acordinating these       11     actions were take? Mow were individuals to the take action     10     11     individuals may be held to be personally responsible.       12     indentified and what information was communicated to the externed second the avartness and interest in the responsible for acordinating these actions and who was responsible for the delivery? What the therein and actions were take? Mow was responsible for the delivery?     10     The influence action action were take?       12     "Fourth, Interferon and Ruberin treatment for HCV."     17     chanesis proposed by Cullen are still robustly managed and could be regarastional       13     response in the sopeified period, I was discharged from the kopping counting comperion was a real test of a counting and communicate to only model     13       14     consideration deliver was a re				
3       HIV and other inflectious agents. It would appear there       3       industry in which I work, we operate in the full         4       has been roluctance by the NHS to accept any       4       knowledge that should there be a major incident,         6       transfusions and blood products, and to then take action       6       main investigation by regulatory agencis. We         8       addressed are: once potential exposure of individuals to       8       individuals may be held to be personally exponsible.         10       this communicated through the organisation? What       10       This responsible for communicated to         11       actions and who are seponsible for coordinating these       11       individuals       7% are acternal example, it is 30 years since the         12       "As an external example, it is 30 years since the       11       individuals       7% are acternal example, it is 30 years since the         13       them? Who was responsible for coordinating these       13       Piper Alpha disster. The Cullen Report resulted in a         14       actions and know are sponsible for the delivery? What is       15       the currention period for these records?         16       the rest ention period for these records?       11       individuals, seered itar, and constantly abject to review, adit and in provement.         16       the currento with combined intheefferon and       18 <td< td=""><td>1</td><td>responsibilities of those controlling these actions?</td><td>1</td><td>effects.</td></td<>	1	responsibilities of those controlling these actions?	1	effects.
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Infected Blood Inquiry - Preliminary Hearing

1	should have been applied across the NHS and by	1	Hepatitis C and, like many people, he remained
2	government in response to these blood infections.	2	undiagnosed for 35 years. He wants the following
3	"Seventh, the Skipton Fund and EIBSS. I only became	3	statement to sink in to everyone for a minute:
4	aware of the Skipton Fund when reading an article about	4	"The NHS just celebrated its 70th birthday, but for
5	the establishment of this Inquiry. As a result,	5	almost 50 years of that time patients have been infected
6	I suspect that there is no routine referral of infected	6 7	or affected from treatments, and left for decades
7	individuals to this support mechanism. Once aware,	8	without any warning that they might have been exposed to infection."
8	I made an application and have been rejected on the grounds that I cannot prove that the infection I had was		
9 10	-	10	By this statement, it is not aimed at the front line nurses, but the people who are in charge of the NHS, the
10 11	the result of NHS actions. Any chance I may have had of proving this causal link has been compromised by the	10	Department of Health and government.
12	retention of only a limited amount of personal data by	12	Today Stuart welcomes the start of the public
12	one hospital and the destruction of all of my files by	13	Inquiry and, as a Core Participant, he is looking
13	another. As a result of the actions of these NHS	13	forward to working with the Inquiry to get to the facts
14	organisations, and given the terms of reference of the	15	and the truth of why this scandal, the biggest scandal
16	EIBSS assessment panel, then I have no ability to prove	16	in the history of the NHS, was allowed to happen.
17	my case.	17	Stuart's hopes are that any person or organisation
18	"I would ask that the Inquiry consider the	18	that is found to have acted negligently, recklessly or
19	following: should it be the responsibility of an	19	irresponsibly, then these people or establishments are
20	individual to prove that HCV was acquired as a result of	20	brought to account for their actions.
20	action by the NHS when supporting information is of poor	20	But, as Sam Stein QC said yesterday about two
22	quality or has been destroyed? Perhaps a fairer method	22	groups, haemophiliacs and whole bloods, there is also
23	would be for the NHS to prove it was not responsible for	23	a third group, the misdiagnosed, so in fact there are
23	the infection.	24	three groups of victims.
25	"Why are elements of the NHS able to destroy patient	25	Some of the issues that are important to Stuart are
20			
	Page 69		Page 71
1	records without the consent of the patient? Such	1	these: firstly, why was this disaster allowed to happen?
2	information may be of value or use in the treatment of	2	Secondly, why were victims tested without their
3	long-term conditions or for epidemiology studies.	3	knowledge?
4	A related but wider consideration is concerning patient	4	Third, why were infections hidden from victims?
5	records not being centralised, but widely dispersed and	5	Fourth, he would like the Inquiry to look at the
6	held only at the point of treatment. As an example,	6	consequences of infections like losing careers,
7	since 1986 I have been registered at four general	7	suffering breakdowns, depression and other mental health
8	practitioners and had treatment at five different	8	issues.
9	hospitals. This does not support good medical	9	Fifth, the impact of regular cancer checks, hospital
10	administration or for instances that require	10	visits and the stress and worry this causes.
11	consideration such as those which this Inquiry is	11	Sixth, what other viruses and infections have we
12	considering. Thank you.	12	been exposed to in the mix of Factor 8 blood products?
13	Opening statement of STUART MACLEAN (read)	13	Things like vCJD and the increased risk of Parkinson's
14	MS FRASER BUTLIN: The second statement that I will read is	14	and Alzheimer's, to name a few.
15	on behalf of another unrepresented Core Participant,	15	Seven, Stuart would like the Inquiry to look into
16	Stuart Maclean.	16	how the government have handled this scandal over the
17	Stuart was given Factor 8 and cryoprecipitate as an	17	last 30 years, as it is shocking, as has been mentioned
18	8-year-old child. Stuart's situation is slightly	18	by others over the last few days. He would repeat:
19	different from many others here today as he's not	19	"We, the sick, now have to fight for justice in this
20	a person with haemophilia, but he has a medical	20	Inquiry, while fighting to stay alive. Sick people
21	condition called Ehlers-Danlos Syndrome, which means he	21	should not have had to fight for so long for justice.
22	has no tissue around his joints and, as such, he bruises	22	The government and civil service should be ashamed.
23	easily.	23	Thousands of lives have been destroyed. Thousands of
24	Stuart was given Factor 8 as a child because of	24	families have had their lives turned upside down and
25	a swollen knee and, as a result, he was infected with	25	thousands have died, and it is still going on today."
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# Infected Blood Inquiry - Preliminary Hearing

26 September 2018

1		1	-11 the ensistence he can be determined
1	Eight, Stuart would also like the public Inquiry to	1 2	all the assistance he can. And he says: "Now let's get this started and hopefully get what
2	look into how the schemes were set up and run: "The schemes were supposed to help us and made us	3	we all deserve: justice and truth."
3		1	-
4 5	beg and have wrongly denied support to hundreds of victims."	4 5	Thank you.
6		6	SIR BRIAN LANGSTAFF: Thank you, Andrew, thank you, Stuart.
7	Stuart would also like to add, since this Inquiry	7	There is a slight change to the programme. Respecting
	was announced by the Prime Minister, that over 80 more	1	the entitlement of Core Participants to be heard, those
8 9	victims have died and that time is of the essence. If fault is identified, there needs to be action taken	8	who are represented through representatives and those
	,	10	who are not, by themselves, or those who will read out their statement for them, it is the wish of
10 11	straight away as the Inquiry goes along, rather than	10	
11	waiting to the end of the Inquiry, because otherwise many people won't live to see justice.	11	Mark Stewart, an unrepresented Core Participant to have his statement read by his daughter Jade.
12	Many victims do not have time on their hands to have	12	Opening statement of MARK STEWART
13	2	13	
14	to sit through an Inquiry and then criminal proceedings like the Hillsborough families and victims have had to	14	JADE: This is a very brief statement:
15	endure. We owe it to all the deceased victims and their	1	"My name is Mark Stewart and I have a mild to
10	families, and the victims remaining that are battling	16	moderate Von Willebrand disease, and I was given contaminated blood, Factor 8, on 12 May 1981, in the
17	this life sentence given to them through no fault of	17	
18	their own, to provide justice.	18	Royal Free Hospital, in London, as just an 11 year old
20	Most of all, Stuart would like the Inquiry to leave	19	boy. I have learnt from my medical records that I did
20 21	1.	20	not require this treatment. I was a previously
21	no stone unturned, looking at every individual company	21	untreated patient or a guinea pig. I contracted
22	or establishment that is in any way connected to this	22	Hepatitis C and was exposed to other fatal viruses
	scandal. Yes, speed is important to him as people are	23	thereafter. But despite this being known to my treating
24 25	dying from this still today, but a total thoroughness is more important than speed.	24	clinicians, I did not find out about my diagnosis until
23	more important than speed.	25	2007, which is over 25 years later.
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1	He also hopes that all those that are involved,	1	Through these years, I had repeated blood tests and
2	particularly government and the NHS, will be very open,	2	monitoring, but was not informed about my condition.
3	transparent and will supply all relevant evidence to the	3	I was given 48 weeks of treatment for Hepatitis C with
4	Inquiry team, so that they can carry out their duties to	4	severe and debilitating side effects, including severe
5	the best of their ability and hopefully, after 30 years	5	psychiatric injuries. I was made to pay for
6	for some victims of campaigning, we will finally get to	6	a substantial part of my treatment myself. The
7	the truth, the answers we crave and closure.	7	treatment was ultimately not successful and psychiatric
8	Finally, what does he intend to add, because he	8	difficulties continue.
9	thinks it's important that all of those infected and	9	"I want the Inquiry to look at why I was treated
10	affected contribute. Stuart has already obtained his	10	with contaminated Factor 8 when this was not necessary
11	medical records and is looking forward to providing his	11	and why I was not informed about my diagnosis at the
12	written statement to the Inquiry and he would urge you	12	time. I particularly want the Inquiry to look at the
13	all, if you haven't already, to take action to obtain	13	position of previously untreated patients, and the
14	yours or your loved one's medical records so that you	14	testing and monitoring of patients that took place
15	can pass these on to the Inquiry or your legal teams.	15	without their consent.
16	You can find guidance about how to do this free of	16	"I have information that can help the Inquiry from
17	charge on the Inquiry website.	17	my medical records and I want to participate with the
18	Stuart runs a Facebook campaign group called	18	Inquiry to help find the answers. The contaminated
19	Contaminated Blood Public Inquiry News, which will	19	blood scandal has absolutely devastated my family. My
20	provide daily updates as the Inquiry progresses. His	20	father and my brother were also given contaminated blood
21	group is open to all victims, no matter how infected or	21	for Von Willebrand disease. As a consequence they
22	affected. If you'd like to join, just get in touch and	22	contracted Hepatitis C, they developed liver
23	you will be welcome.	23	complications and, as a direct consequence of this,
24	Stuart also intends to work closely with the Inquiry	24	died. My brother, Angus, in 2013 and my father, Angus
25	as a Core Participant and he will give the Inquiry team	25	Senior, died in 2002. I will be presenting a much more
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	rage /4		rage 70

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1	detailed statement when instructed and I hope to God	1	of the early infections.
2	that the truth will come out."	2	As with frequent blood transfusions, the risk of
3	SIR BRIAN LANGSTAFF: Thank you, Mark, thank you, Jade.	3	obtaining blood borne viruses increases. Many
4	The next statement is going to be made on behalf of	4	Thalassaemia patients became infected with Hepatitis C
5	the UK Thalassaemia Society. Those of you who have your	5	during the 1970s and 1980s after being given
6	programmes with you, you will see that it was to be by	6	contaminated blood. According to the National Registry
7	Christos Sotirelis. It will be by Roanna Maharaj.	7	for Haemoglobinopathies, it is believed that there are
8	Opening statement by ROANNA MAHARAJ	8	over 1,000 transfusion dependent Thalassaemia patients
9	MS MAHARAJ: Hello everyone. Before I begin, I just want to	9	in the UK. Of these, it is believed that around
10	say that I am in awe of all the stories I have been	10	23 per cent contracted Hepatitis.
11	hearing over the past three days. We felt that we were	11	There was an Italian study done a few years ago and
12	alone in this, but now I know we have a family, even in	12	it is thought that approximately 80 per cent of the
13	this tragedy, but we are.	13	adult patients who received blood transfusions before
14	Before I go on to explain what Thalassaemia is	14	the year of 1991 have been infected by Hepatitis C. Can
15	because most of you I am sure don't know about it	15	you imagine the great scale of this?
16	I am going to tell you a little bit about my story.	16	However, due to the funding restraints placed on the
17	So, I'm a 29-year-old Beta Thalassaemia Major	17	NHS, sufficient emphasis was not placed on
18	patient. What that meant was that I am unable to	18	record-keeping, which meant that the incidents of
19	produce red well, haemoglobin. So, since I was born	19	Hepatitis C for Thalassaemia in the UK is unknown.
20	I have been having blood transfusions throughout my	20	Liver disease and Thalassaemia is a medical
21	life.	21	consequence of both iron load and viral infection mainly
22	Last year alone, I received 110 units of blood and	22	caused by transfusion related Hepatitis viruses. Liver
23	other blood products, and that's just one year. Well,	23	disease is more severe in HCV infected patients with
24	I was lucky to not have contracted Hepatitis during my	24	active infection and this may be compounded by hepatic
25	time. Many of our members in the society and my friends	25	iron overload. It is thus anticipated that the numbers
	Page 77		Page 79
1			
1	have all died from it. So, I really hope this Inquiry	1	of Thalassaemia patients who develop liver cancer will
2	have all died from it. So, I really hope this Inquiry brings the truth out.	1 2	of Thalassaemia patients who develop liver cancer will increase in the future and it will be one of the leading
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	brings the truth out. So, Beta Thalassaemia, as I said, is a life threatening inherited condition in which individuals are unable to produce normal adult haemoglobin. As a result of this, patients become profoundly anaemic and require regular blood transfusions ranging from every two to four weeks, depending on the severity of their case, in order to live. Thalassaemia patients also receive iron collation therapy in order to remove the excess iron they accumulate during these blood transfusions. The excess iron usually deposits in vital organs, consequently leading individuals to develop, although life long complications such as diabetes, osteoporosis, cardiac disease, renal disease, infertility, liver damage resulting in hepatocellular carcinoma, or liver cancer. Until 2008, cardiac iron overload was thought to be the main cause of death in Thalassaemia. Since then, hepatocellular carcinoma has been a growing problem for patients with long-term Hepatitis C infection.	$ \begin{array}{c} 2\\ 3\\ 4\\ 5\\ 6\\ 7\\ 8\\ 9\\ 10\\ 11\\ 12\\ 13\\ 14\\ 15\\ 16\\ 17\\ 18\\ 19\\ 20\\ 21\\ 22\\ \end{array} $	increase in the future and it will be one of the leading clinical problems in Thalassaemia. According to a study done by Borgna-Pignatti, there has been an increase in liver cancer since the 1980s. Consequently, approximately 50 to 75 per cent of these cases have been associated with Hepatitis C virus and with the risk increasing if patients are co-infected with Hepatitis B. Only a few people in Thalassaemia have undergone a successful liver transplantation. A number of these patients have received several cycles of anti-viral treatments between 6 to 12 months over the years, but they were proved to be ineffective for the more severe types of HCV. They increase hemolysis caused by these agents, frequently doubling with the patient transfusion requirement, restricted achieving optimal dosing leading to the treatment failure after a prolonged period of the patients trying to cope with increased treatment relieving iron berthing amongst other things. Now, as you can tell, there is a lot to do with Thalassaemia in one way and now with Hepatitis.
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	brings the truth out. So, Beta Thalassaemia, as I said, is a life threatening inherited condition in which individuals are unable to produce normal adult haemoglobin. As a result of this, patients become profoundly anaemic and require regular blood transfusions ranging from every two to four weeks, depending on the severity of their case, in order to live. Thalassaemia patients also receive iron collation therapy in order to remove the excess iron they accumulate during these blood transfusions. The excess iron usually deposits in vital organs, consequently leading individuals to develop, although life long complications such as diabetes, osteoporosis, cardiac disease, renal disease, infertility, liver damage resulting in hepatocellular carcinoma, or liver cancer. Until 2008, cardiac iron overload was thought to be the main cause of death in Thalassaemia. Since then, hepatocellular carcinoma has been a growing problem for patients with long-term Hepatitis C infection. Fortunately, transmission of Hepatitis C by blood transfusions is now very rare, so the risk may be	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	<ul> <li>increase in the future and it will be one of the leading clinical problems in Thalassaemia.</li> <li>According to a study done by Borgna-Pignatti, there has been an increase in liver cancer since the 1980s.</li> <li>Consequently, approximately 50 to 75 per cent of these cases have been associated with Hepatitis C virus and with the risk increasing if patients are co-infected with Hepatitis B.</li> <li>Only a few people in Thalassaemia have undergone a successful liver transplantation. A number of these patients have received several cycles of anti-viral treatments between 6 to 12 months over the years, but they were proved to be ineffective for the more severe types of HCV. They increase hemolysis caused by these agents, frequently doubling with the patient transfusion requirement, restricted achieving optimal dosing leading to the treatment failure after a prolonged period of the patients trying to cope with increased treatment relieving iron berthing amongst other things.</li> <li>Now, as you can tell, there is a lot to do with Thalassaemia in one way and now with Hepatitis.</li> <li>So, in most communities in which Thalassaemia was predominant and Thalassaemia is predominant in north</li> </ul>

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1	South Asia in these communities there was an enormous	1	and their families?.
2	amount of social stigma associated with just having	2	Now with regards to medical and psychological
3	Thalassaemia. With hours of blood transfusions,	3	consequences what were the other medical consequences
4	chelation therapy, social stigmatisation, mainly because	4	caused as a result of contracting a blood borne virus
5	of the deformed external features that most patients	5	and what treatments, services and support were in place
6	have, social exclusion, patients and their families face	6	to help patients with this?
7	significant psychosocial and emotional distress.	7	Now, bringing the psychological burden to light,
8	For many of the affected persons in the UK, being	8	what about the distress caused to all those who infected
9	a Thalassaemia patient resulted in social	9	and affected, the lives whose dreams were unfulfilled,
10	isolation, marital tensions and stigmatisation. The	10	shattered and destroyed due to the tragedy, the loss of
11	feelings attributed to the psychosocial burden due to	11	educational opportunities, employment, relationships and
12	Thalassaemia were then further reinforced by the stigma	12	overall quality of life affected because of being given
13	associated with Hepatitis C. They combined a range of	13	contaminated blood?
14	factors, including illness related uncertainty due to	14	Now, how are the infected and affected going to be
15	the Hepatitis C diagnosis, prognostic, unpredictability,	15	compensated? Will we get formal apologies from all the
16	stigma and discrimination.	16	wrongdoers? Will the government explain what happened?
17	As well as previously unknown fear of transmission	17	And monetary. Now, there are a lot of patients who
18	to others, they all cause additional stigmatisation and	18	were made to feel that they were begging for charity
19	increase the uncertainty and negativity about the	19	when they applied to the various funds which became
20	future.	20	increasingly difficult to access. Even today with the
21	We can all agree that treatment for Thalassaemia is	21	simple change from the Disability Living Allowance to
22	extremely difficult and challenging in itself. However,	22	the Personal Independence Payments patients are being
23	with the additional burden of Hepatitis life became even	23	sent to tribunals to appeal the negative decisions they
24	more dire, as the treatment for Hepatitis was brutal and	24	received from PIP assessors due to the fact that their
25	in most cases unsuccessful. And with the thought of	25	invisible illnesses doesn't portray on the outside.
	Page 81		Page 83
1	requiring life-long blood transfusions, there was an	1	The members agree with the terms of reference set
2	additional fright whether patients would acquire any	2	out by the Inquiry and we would like the Inquiry to try
3	more blood-borne illnesses. This in turn negatively	3	to obtain all the relevant documentation from the
4	affected the need for wanting to get better seeking and	4	NHS Trust treating Thalassaemia throughout the UK with
5	complying with the vigorous treatment regimes. Denial	5	the aim of trying to find out the exact numbers of
6	was also observed in a small number of families. Some	6	patients infected throughout the years, as we are unable
7	families could not come to terms with Thalassaemia and	7	to find out exactly how many patients have been
8	more or less the reality of their child's new illnesses	8	infected, and if they are deceased to get to the bottom
9	and denied it altogether.	9	of the real cause of death as in some cases the cause of
10	Now, on behalf of our members I would like to speak	10	death was just listed as Thalassaemia. So we don't
11	to the Inquiry about what we think you should focus on.	11	really know what happened.
12	So I know a lot of the people who spoke over the past	12	We hope that the relevant bodies will cooperate with
13	three days spoke about establishing the truth. The	13	this.
14	society would really like a real explanation as to how	14	We are also really interested to work with the
15	this atrocity happened, when did authorities,	15	expert groups and the statisticians and
16	policymakers, the blood service know that the blood and	16	infection clinicians because we have a lot of members
17	blood products they were prescribing and issuing were	17	and they have lived through a lot of circumstances. So
18	contaminated? Who was responsible for continuing to use	18	we'd like to work with them to try to get to the bottom
19	the contaminated products despite knowing it may have	19	of this.
20	been compromised? Why was this injustice allowed and,	20	We hope that by having the Core Participant status
21	if reports are correct, why was it swept under the	21	would mean we will be an active part of the Inquiry and
22	carpet and why were the medical records lost and	22	we look forward to finding out the truth and seeking
23	destroyed? Has there really been a cover-up as the	23	justice for all the patients and their loved ones
24	report say? What steps were taken to explain the risk	24	infected and affected by Hepatitis C and other blood
25	of transmissions of blood borne illnesses to patients	25	borne diseases.
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# Infected Blood Inquiry - Preliminary Hearing

1 Tha	ank you very much for listening to me.	1	delay of this investigation has resulted in many of
2 SIR BRI	AN LANGSTAFF: Thank you very much.	2	those infected or affected not surviving to see the
3 The	e Haemophilia Society are a Core Participant.	3	commencement of this Inquiry. In essence, going to
4 They	are represented by Raymond Bradley. He will now	4	their graves without the knowledge of why their life was
5 come	and address you.	5	cut short and why they suffered to such an extent in
6 (	Dpening statement by RAYMOND BRADLEY	6	advance of their death.
7 MR BRA	ADLEY: Good afternoon, Sir Brian, good afternoon,	7	In addition, the passage of time created additional
8 memb	ers of the public, ladies and gentlemen.	8	psychological trauma for those who have survived to see
9 I ha	we a limited timeframe of 30 minutes within	9	the commencement of the Inquiry process. Government has
10 which	to address you and I am going to condense my	10	provided only subsistence-type payments to ensure that
11 openii	ng statement but I will be delivering a more	11	persons infected or affected would not have the ability
12 comp	rehensive opening statement to the Inquiry in	12	to maintain or advance their own cause in an effective
13 writte	n format.	13	and constructive manner. So, those persons were
14 Als	o at the outset I wish to apologise for my dulcet	14	suffering both ill health and lack of financial capacity
15 Irish t	ones and any lack of eloquence on my part in	15	at that time and, therefore, would have been
16 terms	of the enormity of the personal tragedy that we	16	disadvantaged as a consequence.
17 have l	heard over the last two days.	17	Such a scenario has driven a wedge within the
18 As	Sir Brian has indicated, I am instructed and	18	haemophilia community. As conspiracy theories have run
19 appea	r on behalf of the Haemophilia Society, a legal	19	amok, there was little or limited basis for such
20 entity	that has charitable purpose and represents the	20	perspectives.
21 comm	unity of persons infected and affected by receipt of	21	What is very clear is that vulnerable citizens have
22 contai	ninated blood and blood products due to the	22	been denied justice, resulting in a very inward-looking
23 bleedi	ng disorder conditions. Those persons have lived	23	consequence that ought not to have occurred, but was, in
24 quiet	lives of desperation, suffered in silence and have	24	essence, a consequence of a failure of any proper
25 endur	ed the tragic effect of their quiet lives of	25	humanitarian response by government.
	Page 85		Page 87
	1 490 00		i age of
1 despe	ration and decimated futures.	1	Given the limited time frame, as I indicated, a more
2 Th	e Society carries a huge burden and has done so	2	comprehensive opening statement will be filed with the
3 for m	any decades in terms of provision of support to its	3	Inquiry. We are now at the end of two days of opening
4 memb	pership. For many decades it has criticised	4	statements, all of which have been very eloquent and The
5 gover	nment for its paltry, subsistence-like subventions,	5	Society supports and endorses each and every view that
6 that h	ave added insult to injury and have created a fear	6	has been put forward to the chairperson.
7 within	n its community to take on the might of that	7	Many of those infected and affected have canvassed
8 Gove	rnment because of the potential withdrawal of the	8	through The Society and, indeed through the other
9 subsis	stence.	9	representative bodies Haemophilia Scotland,
10 Th	e Government has been anything but empathetic to	10	Haemophilia Wales and Haemophilia Northern Ireland to
11 the co	onsequences that have befallen you, as a very	11	seek justice over the years. I now wish to focus on
12 tragic	group of people. It should be remembered that	12	that justice and how The Society, my clients, will fight
13 any n	ation is judged or assessed by the way it treats	13	for justice for those infected by contaminated by blood
14 its mo	ost vulnerable citizens in their greatest hour of	14	products and their families.
15 need.		15	Since the effects of this tragedy came to light,
16 Th	e Society, it should be remembered, comprises some	16	they have worked to improve healthcare entitlements,
17 5,000	members. It is an organisation that has	17	provide support and deliver care to those affected.
18 repres	sented myriad interests, most particularly relating	18	Many of the trustees of The Society who commenced that
19 to the	se infected and affected over the past 33 years,	19	work are no longer with us today. We remember their
20 since	the plight of HIV has reared its ugly head. There	20	work and their objective was achieving truth and we hope
21 is an	old legal concept, the concept of justice being	21	now to be able to deliver that for them through your
22 delay	ed is justice denied and it is very apposite in	22	work.
23 your	circumstances.	23	The Society accepts that it ought itself to be
24 An	inquiry process ought to have occurred many	24	investigated in relation to the various perceptions or
25 decad	es ago, but the consequences associated with the	25	criticisms that may exist, in terms of its actions or
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1	inactions, and it welcomes such scrutiny as it allows it	1	our clients', members and perceptions to this day.
2	an opportunity to be open and transparent in association	2	Accordingly, government, in terms of doing the right
3	with the events which so occurred.	3	thing, have maintained their policy of deleteriousness.
4	Yet more than 30 years ago the Haemophilia Society	4	I am going to bring you back through a little history.
5	called upon government to launch a public Inquiry into	5	A legal action was launched in 1990. When matters
6	the infection of those thousands of its members with	6	were due to proceed to court government was encouraged
7	contaminated blood and blood products, and what has been	7	yet again to do the right thing by vulnerable members of
8	correctly termed during the course of the past two days	8	this nation, you. Somewhat uniquely, a very learned
9	"the worst treatment disaster in the history of the	9	judge, who was due to hear the case, Mr Justice Argyle,
10	NHS".	10	wrote directly to government as is referenced in his own
11	The Society demanded an immediate humanitarian	11	memoirs. Also, privately, he wrote to the then
12	response by government. After decades, and what I can	12	Secretary of State for Health. He set out what might be
13	only term an unconscionable delay, at least 2,400 people	13	described as the moral dimension in this case. He said:
14	have died and many thousands more, who were needlessly	14	"A government which takes upon itself the role of
15	exposed to Hepatitis C and HIV, continue to suffer with	15	public provider of medical advice and clinical service
16	life changing consequences.	16	is in a very different position to any commercial
17	Those persons, as I have indicated, have lived quiet	17	organisation. It is clearly arguable that their duty to
18	lives of desperation, endured decimated futures and	18	innocent citizens who suffer injury under the aegis of
19	indeed suffered destruction of life itself. Eventually,	19	such treatment has a moral dimension which should
20	government has finally begun to listen and has	20	distinguish the assessment of their position from the
21	established this Inquiry.	21	criteria to be adopted by the defendants of a corporate
22	It should be remembered the first duty of any	22	character."
23	government, in any jurisdiction, is to protect its	23	So, he went on to say:
24	citizens. If government fails in that duty, its	24	"Government owes a duty wider than to its
25	secondary duty must be to do all in its power to redress	25	shareholders and its insurers. It should also mean that
	······································		
	Page 89		Page 91
1	the initial and a Wet in the simulation of a second		4
1	the initial wrong. Yet, in the circumstances of persons	1	the public may be entitled to expect from a government
2	infected and affected by receipt of contaminated blood	2	an appraisal of their position which is not confined
2 3	infected and affected by receipt of contaminated blood and blood products, government has consistently looked	2 3	an appraisal of their position which is not confined solely to legal principles to be found in the laws of
2 3 4	infected and affected by receipt of contaminated blood and blood products, government has consistently looked the other way and, indeed, refused to acknowledge the	2 3 4	an appraisal of their position which is not confined solely to legal principles to be found in the laws of negligence or indeed proof."
2 3 4 5	infected and affected by receipt of contaminated blood and blood products, government has consistently looked the other way and, indeed, refused to acknowledge the true scale of the personal and humanitarian disaster.	2 3 4 5	an appraisal of their position which is not confined solely to legal principles to be found in the laws of negligence or indeed proof." He went on to describe your plight, the victims, as
2 3 4 5 6	infected and affected by receipt of contaminated blood and blood products, government has consistently looked the other way and, indeed, refused to acknowledge the true scale of the personal and humanitarian disaster. It has been complicit in the covering up of this	2 3 4 5 6	<ul><li>an appraisal of their position which is not confined solely to legal principles to be found in the laws of negligence or indeed proof."</li><li>He went on to describe your plight, the victims, as a special one.</li></ul>
2 3 4 5 6 7	infected and affected by receipt of contaminated blood and blood products, government has consistently looked the other way and, indeed, refused to acknowledge the true scale of the personal and humanitarian disaster. It has been complicit in the covering up of this immense human tragedy. For over 30 years various	2 3 4 5 6 7	<ul> <li>an appraisal of their position which is not confined solely to legal principles to be found in the laws of negligence or indeed proof."</li> <li>He went on to describe your plight, the victims, as a special one.</li> <li>The response to that plea by the UK Government of</li> </ul>
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# Infected Blood Inquiry - Preliminary Hearing

1	going to refer as the second excerpt:	1	government failed to adequately deal with that tragedy
2	"In the present case, the government has not	2	and yet again put in place a further form of
3	accepted that the infection of haemophiliacs with the	3	subsistence. Such a subsistence is not fair and
4	AIDS virus tragic as it is was the a result of	4	equitable compensation, nor indeed did the government
5	negligence; or that we should depart from the view	5	provide adequately for the needs or requirements of the
6	reached by the Pearson committee when it rejected the	6	persons infected or affected.
7	arguments of some Genus scheme with no form of	7	The consequences of subsistence payments is that
8	compensation. In the meantime, I can assure you that we	8	persons are placed in a position of vulnerability and
9	are doing all we can to help the court action towards an	9	need with the inevitable effect that such persons are
10	early outcome.	10	made to feel in some way beholding for such payments.
11	"If there has been delays from the original	11	That is not an appropriate response of a government who
12	timetable, that is because of the inherent complexity of	12	has a humanitarian perspective upon matters, but in
13	the issues and certainly not because of any deliberate	13	essence it is the response of a government who seeks to
14	attempt on any side to delay things. I'm sorry if this	14	achieve benefit at the expense of its own vulnerable
15	is a disappointing reply. Yours sincerely,	15	citizens, you.
16	Margaret Thatcher."	16	Once again, the magnitude of the infection with
17	Persons with haemophilia, at that time, were dying	17	Hepatitis C, when it became known, resulted in
18	as the complexity of the issues delayed matters.	18	government failing persons infected and affected. The
19	Although there was purportedly no attempt on any scale	19	government failed to adequately deal with the tragedy
20	to delay things.	20	and yet again put in place what I can only describe as
21	The government abdicated its responsibility to do	21	a further paltry form of subsistence. It failed to
22	the right thing by the haemophilia community and hid	22	properly compensate for the devastating consequences
23	behind the concept of litigation to avoid its moral	23	visited upon your community.
23	responsibility to you or to respond to the consequences	24	Yet again people died without dignity, without
25	of HIV infection.	25	knowing what would become of their family members whose
20		20	and wing what would become of their failing memories whose
	Page 93		Page 95
1	The true response of government has been to take	1	life path had been altered by virtue of the lack of
2	advantage of its own volume of solicitors, who in this	2	financial resources available to them due to illness and
3	instance were members of the haemophilia community, who	3	the debt of their family member. Also, such persons
4	at their greatest hour of need were obliged to sign up	4	went to their graves not knowing what had occurred or
5	to a financial system to which every person who was so	5	achieving any semblance of justice.
6	infected had to commit, and a form of moral blackmail.	6	I wish to refer to another letter. This letter is
7	If everyone did not sign up, there was no benefit.	7	dated 16 May 1996 from then Prime Minister John Major,
8	That system paid minimal subsistence to those	8	and it indicates a very clear attitude of government and
9	infected and affected and, in addition, had the	9	its perception of its duty to its most vulnerable
10	beneficial effect, from the government's perspective,	10	citizens:
11	that its acceptance denied the haemophilia community to	11	"The government has given the question of
12	seek fair and equitable compensation.	12	compensation very careful consideration, including the
13	This stroke and there is no other word I can	13	Irish scheme. I have great sympathy, but I really do
14	use was pulled by government on its own most	14	think it is better to spend money provided for
15	vulnerable citizens at their most weak time.	15	healthcare, from whatever source, on treating patients
16	The Society, for whom I act, view such actions as	16	than on payments to people who received the best
17	a cruel and calculated attempt to subjugate its	17	possible treatment available at the time."
18	community into submission.	18	I don't think many people in this room would agree
19	Also, government insisted that the haemophilia HIV	19	with that statement:
20	community sign away any rights to any further action	20	"I am convinced that the best way we can provide
21	relating to Hepatitis C. Those persons had no knowledge	21	practical help is to encourage research and best
22	of what Hepatitis C infection meant or even the	22	treatment for those infected, as well as supporting
23	potential legal consequences.	23	voluntary groups directly concerned with their care. We
24	Yet again, in relation to Hepatitis C, and sadly	24	shall continue to support these efforts and explore
25	once the magnitude of that infection became known, the	25	other ways in which we can provide help.
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1	"I am unable to comment on the possibility of any	1	suffer consequences. Such families, and many people in
2	commercial company accepting liability through funding	2	this room, are left in emotional and financial turmoil
3	a settlement and I do not think it would be appropriate	3	and continue to be beholden to government in relation to
4	for us to explore that.	4	subsistence-type payments. Government's failure to
5	"It is therefore possible that haemophiliacs and	5	adequately compensate unlike my own country, Ireland,
6	those suffering from Hepatitis C might be able to	6	where the situation I would say was addressed, after
7	benefit from lottery grants, but this would be a matter	7	a time, in a compassionate, humanitarian and appropriate
8	for the board to decide in response to any applications	8	manner means that the haemophilia and whole blood
9	received."	9	community continue to be treated as second class
10	In short, the assistance contemplated or considered	10	citizens in receipt of subsistence for what your
11	to be appropriate by UK Government was the prospect of	11	Prime Minister said was "lottery payments". Although
12	seeking lottery grant funding. That was their response	12	financial recompense will never heal completely the
13	to the worst treatment disaster in the history of the	13	wounds that have been left to expand over decades,
14	NHS.	14	creating turmoil, adversity and anxiety for families,
15	Also, government, I would submit, laboured under the	15	however, even at this late remove, some effort that is
16	misapprehension that they had provided the best possible	16	reasonable by government would be the commencement of
17	treatment at the time.	17	the healing process.
18	More than three decades later, the government	18	Having ignored the moral dimension, previous
19	finally offered an apology in the House of Commons. On	19	governments, present government and, indeed, in
20	25 March 2015, the then Prime Minister David Cameron was	20	particular the present Prime Minister ought now to act
20	asked to ensure that it was a full apology, transparent	20	on her own moral imperative. It is now time for this
22	publication of all the proper compensation for the	22	government, your government, to make good on its
23	families terribly affected by this scandal. The	23	apology. Also, it is time the government commence the
24	Prime Minister answered:	24	process of allowing healing to occur. It is a time to
25	"I can do all of the three things he asked for."	25	show that when government speaks it is not just for
20	real do an or the aree anings he asked for.	25	show that when government speaks it is not just for
	Page 97		Page 99
1	To this date, that particular commitment still	1	delivering platitudes as in past decades, but it is now
2	remains outstanding. Prime Minister David Cameron	2	acting to address the injustices of this heinous
3	indicated to each and every one of these people he would	3	tragedy. Now is the time to ensure that no one who is
4	like to say sorry on behalf of the whole government for	4	infected or affected continues to suffer in a manner in
5	something which should not have happened.	5	which so many have before and you have so eloquently
6	On announcing the establishment of the Infected	6	outlined.
7	Blood Inquiry in 2017, Prime Minister Theresa May	7	Now is the time to ensure that, in time, those
8	acknowledged the following:	8	persons with a destroyed quality of life and those with
9	"The contaminated blood scandal of the 1970s and	9	decimated futures can exit life with dignity safe in the
10	1980s is an appalling tragedy. It should simply never	10	knowledge that those who are family members or loved
11	have happened. Thousands of patients expected the world	11	ones are appropriately provided for.
12	class care our NHS is famous for, but they were failed.	12	Now is the time to ensure that those who remain will
13	At least 2,400 people died and thousands were exposed to	13	no longer have to fight unnecessary and divisive
14	Hepatitis C and HIV, with life changing consequences."	14	battles. Although justice delayed is justice denied,
15	She also said:	15	and it has been delayed, any justice at all, even at
16	"The victims and their families, who have suffered	16	this late remove, will be welcomed by you. Now is the
17	so much pain and hardship, deserve answers as to how	17	time to ensure that that justice is finally delivered.
18	this could possibly have happened."	18	Successive governments have been the problem, who
19	She went on to indicate:	19	were unwilling to acknowledge the true extent of the
20	"As Prime Minister, I am determined to stand up for	20	health catastrophe that occurred and the moral
21	victims in confronting justice and unfairness in society	21	obligation that arose. The Government must now be part
22	at every turn."	22	of the solution. The setting up of this Inquiry is an
23	Whilst many of the infections that have tragically	23	incredibly welcome step. The work that this Inquiry has
24	occurred happened over 30 years ago, those infected	24	to undertake is incredibly important. Also, the
25	continue to die. The families affected continue to	25	apologies of government so delivered and the empathetic
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1	indications of annual control data in the second	<sub>1</sub>	Mara amaially, as accumred in Iroland it is
1	indications so provided are welcome. However, if this	1 2	More crucially, as occurred in Ireland, it is necessary that a compensation issue is addressed before
2 3	is to mean anything, government must ensure full and candid disclosure of what went wrong and why.	$\begin{vmatrix} 2\\ 3 \end{vmatrix}$	
3 4	Government should not rely upon legal professional	4	the conclusion of this Inquiry. We had compensation before the investigation was completed. Where you, as
5	or public interest privilege in the context of this	5	chairperson, have the entitlement to make an interim
6	Inquiry. In Ireland, the government waived that	6	recommendation, the Haemophilia Society requests that
7	privilege in the Lindsay tribunal and it should be	7	the current postcode lottery of subsistence benefits
8	sought by the Inquiry that it waives, as a matter of	8	would immediately cease and, as an interim measure, that
9	policy, its privilege in relation to sensitive	9	the support available in Scotland would become widely
10	documentation so that an all encompassing inquiry can	10	available. Also, that the issue of compensation be
11	occur and you can get the answers you deserve.	11	addressed on the basis of the Irish scheme model on
12	In Ireland during the Lindsay tribunal the	12	a moral responsibility basis pending the conclusion of
13	government waived that privilege. I have to say, much	13	this investigation or Inquiry, as requested all those
14	of the interesting documentation that became available	14	many decades ago by the very prescient
15	during that Inquiry was the so-called privilege	15	Mr Justice Argyle.
16	documentation. If the apology that has been delivered	16	I want to touch on an issue that's a very sensitive
17	is to mean anything, action unfair and equitable	17	issue, but I think it is necessary that we consider it
18	compensation must now follow long before this Inquiry	18	in the context of the Inquiry's work.
19	concludes its investigation. Time is of the essence.	19	Support in counselling. This Inquiry will
20	The model exists in my home jurisdiction, which	20	inevitably take the infected and affected on a roller
21	I framed, that has been in existence for more than	21	coaster emotional journey, which will reveal old wounds
22	20 years, to alleviate, healthcare concerns, the	22	and create new wounds and obliterate the coping
23	financial requirements and to provide insurance cover	23	mechanism of denial.
24	for people infected and affected.	24	In short, what is termed by consulting psychologists
25	This allows people to live with some dignity in the	25	as both retraumatisation and overcoming denial will
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	~		
1	context of their own quiet desperation. This allows	1	occur. Essentially, this means the re-experiencing of
2	people to have some confidence in what future exists for	2	emotions connected to past traumatic events. This
3	them. Also, the widows and the children of those	3	psychological impact of events thus far cannot be
4	persons who have died are fairly compensated through the	4	underestimated. Many would be suffering already with
5	entitlement of applications, loss of society claims	5	undiagnosed psychological and perhaps psychiatric
6	et cetera. If matters here, in this country, are	6 7	consequences. The Inquiry process must be sensitive to
7 8	allowed to continue to fester, where government remains inactive, then the apology of government, the empathetic	8	such a scenario and provide comprehensive psychological
8 9	indications are hollow in the extreme.	9	and psychiatric supports at all stages, to those who will be both attending the Inquiry and indeed to those
10	Accordingly, the Haemophilia Society calls upon the	10	who are following its work from a distance. It is
10	present government, under Prime Minister Theresa May, to	11	essential that this already fragile community is not
12	provide immediate action in the following areas: (1)	12	further damaged.
12	financial support. At present differential financial	13	Many persons who have lost loved ones are outside
13	arrangements exist, depending where victims were	14	the healthcare system and are not in contact with any
15	infected in the United Kingdom. You, as the infected	15	support service, so it is essential that such
16	and affected, are subjugated to a subsistence method	16	a potential failure is addressed. The Inquiry team has
17	that is dependent on a postcode lottery.	17	announced the availability of counselling support during
18	At the very least, as an interim measure, all should	18	these opening days of the Inquiry, which is very much to
19	be eligible for the same financial arrangements as exist	19	be welcomed. However, based upon my experience, in my
20	in Scotland. Such a concession by government is only	20	home jurisdiction of representing many, many people,
21	a start and is not the end of matters. Government ought	21	I believe that a much more permanent and indeed more
22	to address the fair and equitable compensation situation	22	comprehensive system must be set up as a matter of
23	they had previously refused in the context of	23	priority to provide an appropriate compassionate
24	John Major's letter relating to the Irish compensation	24	response to people's needs and requirements as the
25	scheme.	25	Inquiry progresses.
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1	I have taken advice from psychologists who work with	1	already on the neuroll
2	people in your situation, and that is their	$\begin{vmatrix} 1\\2 \end{vmatrix}$	already on the payroll. Equality of participation means equality of
3	recommendation.	$\begin{vmatrix} 2\\ 3 \end{vmatrix}$	resources. To participate as a Core Participant nothing
4	It would be fundamentally wrong and, indeed,	4	less is adequate. No constraints apply to government or
5	potentially catastrophic to vulnerable persons of this	5	indeed pharmaceutical companies, in terms of resources.
6	Inquiry to create through its very necessary work	6	So, you need to be able to be represented on an equal
7	a retraumatisation situation where, yet again, your	7	basis.
8	community is left to its own devices to address such	8	I wish to endorse the comments that have been made
9	-	9	
-	a scenario without the appropriate expertise or response or supports being provided.		today in relation to medical records. Every personal
10		10	statement I believe necessitates the ability to review,
11 12	The Inquiry has requested contributions on	11 12	as a prerequisite, assuming the medical records are
12	procedural issues. I intend to address those exact	12	available, those medical records. To do otherwise
13	issues now based upon my own past experience of	13	creates a potential injustice for you. This is your
14	inquiries. This is my third public statutory Inquiry	14	only opportunity to tell your story, which ought to be accurate. You are entitled to know whether you have
15	into the contamination of blood and blood products. It	16	
10	is my first in the United Kingdom.	17	been informed of your diagnosis in a timely manner, whether there was any other information relating to you
	The Society's members wish to participate in a comprehensive proactive and effective manner during	18	in the medical records that you would like to comment
18		18	-
19 20	the course of the Inquiry's investigation. To achieve	20	upon in your statement, all other inquiries have used medical records as a crucial and essential source of
20	its members' objectives I believe the following requires	20	
	to occur: (1) that all Core Participants have access to		information. The time period of 21 days from the date
22	all discovery documentation. This has already been	22 23	of cost entitlement to prepare a statement is extremely
23	indicated as being a right;		limited. Obtaining the records and reviewing the
24	(2) That all Core Participants have the ability to	24	records, which are undoubtedly extensive and comprise
25	indicate what documents should be utilised as part of	25	many medical charts and are often located in various
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1	a core booklet for the examination of witnesses;	1	hospitals, is a timely process. Often interviewing
2	(3) That each Core Participant has a right or	2	people for the purpose of taking statements is a very
3	entitlement to examine witnesses in accordance with its	3	difficult situation for them and can take a number of
4	legitimate interests under the terms of reference	4	meetings.
5	arising from its core participant status.	5	All of the foregoing presupposes the ready
6	As I said, I have concluded two inquiries. In both,	6	availability of the entire medical records. I believe
7	I represented victims like you. In both of those	7	that there is a necessity for medical records to be made
8	inquiries that was the right of entitlement that was	8	available for each and every person to be able to
9	available. Anything less I believe is inadequate	9	prepare their statement. I think there is a requirement
10	participation and, more crucially, it is unfair to	10	for efforts to ascertain why so many medical records are
11	expect the Inquiry team itself to represent conflicting	11	not easily accessible, and that's an issue that needs to
12	issues on any particular topic.	12	be addressed as a prerequisite.
13	Also, I would emphasise the equality of resources	13	It should be remembered that the medical records are
14	ought to apply to all Core Participants. In public	14	essential in relation to the following: ascertaining the
15	statutory inquiries I have seen victim groups and I have	15	infected product, ascertaining when the patient was
16	experienced the consequence, have been entitled to	16	informed of their diagnosis and whether it was timely,
17	participate on an equal footing of resources. With	17	ascertaining if there were any physical examinations for
18	government and others a true subvention of the necessary	18	signs of AIDS, ascertaining the first abnormal liver
19	expertise that is required by way of medical and	19	function test for bloods.
20	scientific and other input.	20	Core Participant status for the victims is to put
21	If the Inquiry itself needs an expert panel to	21	the people at the heart of the Inquiry. Failing to
22	assist it, it is no different for the victim groupings.	22	address these issues or anything less diminishes,
23	The government bodies already have access to the	23	potentially, the quality and extent of your legal
24	necessary haematological virological and viral	24	representation, and therefore your participation.
25	inactivation and other similar expertise. They are	25	I am very much against time, so I am going to
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1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25	<text><text><text><text><page-footer></page-footer></text></text></text></text>	1       SIR BRIAN LANGSTAFF: Let's take a break then, now, and it         2       will be until 2.15.         3       (1.15 pm)         4       (A short break)         5       Opening statement by STEVEN SNOWDEN
1 2	attached to the New York blood centre, who undertook assessments and confirmed the ineffectiveness of the	
3	heat treatment process. That company suppressed that	
4	research. The effect was that the product continued to	
5	be distributed. That product was utilised in Canada,	
6	and was the subject and cause of infection of Canadian	
7	people with haemophilia.	
8	Subsequent to the Krever Inquiry there was	
9	a criminal prosecution and	
10	SIR BRIAN LANGSTAFF: Mr Bradley, would you like to take the	
11	next five minutes of what you have to say after lunch?	
12	We have to respect those who are preparing the lunch	
13	for everyone and they I think might like to hear you	
14	shortly after the break. How much longer do you think	
15	you might have? Bear in mind that the timetabling was	
16	done carefully to ensure that people had a fair	
17	opportunity to speak and you agreed to a time limit,	
18	which you are somewhat in excess of. I am not	
19 20	objecting, but there we are.	
20	MR BRADLEY: Unfortunately, my clients have got 50 per cent	
21 22	of the time of any of the other representative groups.	
22 23	SIR BRIAN LANGSTAFF: This is not the time for an argument about it, this is the time for lunch.	
23 24	MR BRADLEY: I appreciate that, and I'm happy to go to	
24 25	lunch.	
20		
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