Tuesday, 25 September 2018
(10.00 am)
Introduction by SIR BRIAN LANGSTAFF
SIR BRIAN LANGSTAFF: Good morning, all. Thank you very much.

Now, a couple of notices for you. Yesterday, we began with that very moving commemoration. There may be some of you who were not here, or some who were here, but would have wanted to add their message to it. If you do, you can go to the chapel where the white container of all the messages is. There are spare bottles and you have an opportunity to add your message if you want.

I have been asked to remind you that if you want to visit the campaigner's room, it is just next to, near to the chapel. Indeed, if you feel moved and troubled at all there is confidential support available in a room just next to that.

So, those are the notices. This morning we have the pleasure of listening, first, to Aidan O'Neill QC on behalf of those largely Scots represented by Thompsons. He will take until 11 o'clock or thereabouts. We may add a couple of minutes to that because we have started a little late, and I would ask those who are to speak to try to keep to timings if they can. It is to give

everyone the best that we can do in terms of fair shares in the time available.

He will be followed, at 11 o'clock, by Della Ryness-Hirsch, the first of our unrepresented core participants. Enough from me, I want to listen to what Aidan O'Neill has to say.

Opening statement by AIDAN O'NEILL
MR O'NEILL: Thank you very much, Chair. I'm Aidan O'Neill and I appear along with my learned friends, counsel, Jamie Dawson and Kirsten Sjøvoll, on behalf of almost 250 core participants, who are infected and affected clients represented before the Inquiry by Thompsons.

We've prepared a written opening statement, which is fairly long, it has to be said, but it is because it has been prepared in a participatory manner as much as possible. So, what is being said is being said by, as much as on behalf of, those whom we have the privilege to represent. This written statement is, I think, being placed on the Inquiry website and is available to all to read at leisure.

So, what I would propose to do in this hour or so that I have -- and I really don't want to try your patience -- is pick up some of the themes which we have set out in that written statement, but not necessarily take everything from it.

So, first of all, the very fact that we are being asked to give an opening statement shows a major difference from the manner in which the previous Inquiry, which many of those whom I represent were involved in Scotland; that is the Penrose Inquiry, where there was no opportunity for any kind of opening statement. Where, as I understand it, the only statement from the Chair there, at the start, was to remind anyone present that money spent on the Inquiry was money taken away from front line NHS care.

That is not an attitude which we think is being repeated here. We are sure it will not be. We are hopeful that this Inquiry will be able to properly and fully answer the so many questions which have been raised by those whom we represent, those questions which for us were left unanswered by our experience in the Penrose Inquiry.

The Penrose Inquiry and our experience in it, in a sense, is still useful and we'll come on and set out why because some of the evidence, which will be relevant to this Inquiry, was heard and discussed there.

So it is not just individuals whom I represent, but also the charities, Haemophilia Scotland and the Scottish Infected Blood Forum. They have campaigned for many years in seeking to represent the interests and

ensure respect for basic rights.

It is the basic rights of the infected and affected which have not been respected in the many years in which you have had to live through this contaminated blood disaster.

We represent individuals who have been infected and affected by all blood borne pathogens, Hepatitis B and Hepatitis C, clearly, HIV, and we note that variant CJD is also expressly mentioned in the terms of reference.

Our experience is that the injury and the deaths, in many cases, which have been suffered, have resulted from wrongful acts on the part of those responsible for providing supplies of blood and blood products.

So, the Inquiry is, for us, an exercise, clearly, in establishing the truth of what happened, in bringing past and ongoing wrongs. Past and ongoing wrongs. This is not something which is finished. Bring those wrongs to light. To learn the lessons from the disaster, to protect all patients who rely on the NHS for safe treatment.

We want the Inquiry to call those responsible for those past wrongs and failings to account. We want the Inquiry to provide an opportunity for those who were responsible for those wrongs to acknowledge and accept responsibility for them, that what was done by them

and/or on their watch.

We want the Inquiry to be that space in which they can apologise fully, and unreservedly and unequivocally for the harms which you have suffered.

Now, I have spent the past couple of weeks going round different parts of Scotland meeting with some of the 250 or so people I represent. So, as I say, this statement is very much drafted by them as much as by the lawyers.

I want to set out a few of the things which I've learned in that time, and it has been very much a learning experience for me.

So, first of all, I'll talk to you about the clients I represent and their experiences. Much of it is familiar to you. The fact is it is unfamiliar to me, and that's the shocking part. You know what you've gone through and so much of the rest of society didn't know that. So, my meeting those clients, as I say, has been a revelation.

It is right and proper that it is your experience of the infected and affected which is being placed, in the words of the Chair, "front and centre". You are physically front and centre. You will be, I hope, at all times and in all aspects of the manner in which the Inquiry is run.

It is the hearing and heeding of stories of the infected and affected, only by doing that that the Inquiry can properly conduct its business and fulfil the hopes and expectations which have been invested in it.

As I say, I have been humbled by what I have heard, by people whose lives have been blighted and burdened by infection. I have heard the righteous anger.

When I appeared in Glasgow, one woman said to me, "Tell them we're not grateful, we're angry. Tell them it's about bloody time". And it is. So much time has been lost in coming here, so much time has been stolen from those whose lives should have been otherwise. It is also about time, in the sense that who knows how much time any of us have before us, so there is clearly a desire, a wish, as the Chair has said, that the Inquiry is done with all due deliberate speed. That it not be rushed, but it be done efficiently, and thoroughly and properly, but there not be undue delays built into matters, because time is one thing that we've spent too much of on this and don't have very much left.

I'm preaching, as it were, to the converted. You know your stories. I don't have to tell you what it's been like and the variety of experiences which you have undergone. The fact that people from all walks of life, all social classes, all backgrounds, all ages have been

affected and infected, but there are some common themes from that diversity.

One common theme is that everyone has placed their trust, put themselves in the hands of health professionals. When they needed their help, when they were at their most vulnerable, they trusted the doctors to whom they turned, they trusted their medical expertise, they trusted they would get the best help and care available. They presumed they would only be treated with safe products and therapies, and they thought that the government would ensure that all those trusts were fulfilled.

Instead of this, there are people who attended and sought healthcare came out not healthier, not cured, but instead crucially weakened in so many ways. Their health, in many cases, fundamentally, permanently and irretrievably compromised. Left with threatening diseases, left with therapies and treatments for those diseases and conditions, which in some ways felt even worse than the conditions which they were left with. Left with subject to debilitating and sometimes experimental and untried therapies that left them permanently weakened and not even clear of some of the viruses.

That has left many with a sense of their faith in

the system shattered and a feeling, then, that faith has not been restored because what they've been faced with has been stonewalling, secrecy, invasion, evasiveness about the condition, a lack of candour.

And people have been left fearful. Their lives, in many cases, have been dogged by depression about their present lives and anxiety about the future. People have lived and died in the shadow of infection. The lives that were left to them were not the lives they were supposed to lead. Those lives were stolen from them.

As I say, what people have told me is what they want is answers, they want matters to be uncovered. They want acknowledgement of what happened to them, and we are very encouraged from the opening of this Inquiry that all those promises have been made.

My task, which I have been asked to do, in some ways is to hold the Inquiry to account, to make sure that it lives up to those hopes and expectations that have been invested in it.

We are, after all, as was said by another one, another person, with whom I had a meeting, we are core participants; the clue is in the name. Those whom I represent are ready and willing to participate in the process, they expect to be able to do so. They expect to be fully participating. Their experience in the

Penrose Inquiry has to be -- only a very few of the affected and infected were allowed to be designated as core participants, but, even there, they were sidelined, and that was their feeling at least. Their feeling was that Inquiry was captured by the medical establishment and was biased against hearing the voices of patients and their families. The result was that Penrose, rather than giving the possibility of being able to live through and have some kind of closure on matters, simply added to that sense of frustration, of rejection, of loss.

We don't want this Inquiry to end up with that similar loss of hope.

That means, Sir, if I may, that one of the main issues which has come out in the meetings I have had is the need to investigate and expose the extent of cover up.

Now, "cover up" sounds like conspiracy theories writ large. The number of people who have spoken to me independently, have come up with such similar stories of medical records that disappeared, of medical records apparently filleted through, so that evidence or record of actual treatment has gone.

Now, if it happened in one case, one would think it was incompetence or just lack of proper systems for

retaining records, but it has happened in so many cases. We want to know why. How has that happened?

Because the problem is, with a lack of trust, then one's faith is broken and what's replaced by it is, to an extent, the idea of conspiracy. Now, we don't want that. We want to ensure that issue is fully raised, aired, investigated, frowned upon.

People looked to other parts of the world where there have been criminal prosecutions. People have looked to, for example, Ireland, where victims have been better treated, in terms of financial compensation, than they have to date in the United Kingdom. Although, I have to say and admit, that in Scotland some of the provision, financially, has been better than in the rest of the United Kingdom, but just because it's better doesn't mean to say it's enough.

So, the aims of the Inquiry. There's a whole series of aims for public inquiries. The first one, obviously, is the issue of establishing the facts and, as you, Chair, have said, that you intend fully, fairly and fearlessly to investigate and expose matters to public scrutiny, and we support you fully in that.

There are still a number of facts, a lot of facts which need to be uncovered, even after the experience of the Penrose Inquiry, for us. But, as I say, I think

it's useful for the Inquiry to hear what we think can be drawn from the Penrose Inquiry, so there isn't needless duplication of matters and that we can work on this efficiently and properly, with all due deliberate speed.

The Penrose final report is a comprehensive work, or is certainly very big. It is five volumes, almost 2,000 pages, the executive summary runs to 45 pages. There was an initial part of the Inquiry with a preliminary report before anybody among the infected or affected was involved going to 614 pages. Now, that has useful material. It can be mined usefully for some of the chronology, some of the factual matters in terms of medical practice and the like.

There is a lot of good scientific information contained in that, particularly a useful account of some of the uncontentious scientific aspects. There's a useful chapter on heat treatment of products, at least in Scotland.

But where we feel that Penrose failed was that it didn't go further. It is simply a great one for setting out what it said what the facts were without asking: well, why did those things happen? How can they be judged? Who was responsible for them?

And we say that is an essential part of this Inquiry, and that that judgment is not, as it appeared

to be with the Penrose Inquiry, simply about what was the general, accepted medical practice in the 1970s and 1980s? What did responsible doctors do? We are judging this with our standards, with what we know, with our standards in the present to say that it may have been what they did, but that doesn't make it right.

One of the issues we had with the Penrose Inquiry, also, was the language which was used in the report. It is not just what you say, it is how you say it. The language of the report, ultimately, was very careful, very measured, very lawyerly.

Careful words like things were "unfortunate", or "we found no evidence of failings", or that certain matters were "noted". For example, the fact that donors with a history of blood transfusion or haemophilia were excluded from donor sessions from May 1983. But there wasn't any analysis, there was no attribution of responsibility for matters which were" "noted".

Then, for example, the difference in treatment about donor exclusion as between the East of Scotland and the West of Scotland referred to the differences being -- one being a less constructive approach. So, again, passing comments. No analysis. No attribution of responsibility.

The possibility, for example, of the cessation of

concentrate use for bleeding disorder patients in response to the growing knowledge that there was an issue and a threat of HIV; the idea that could be stopped was dismissed as a minority view, rejected by a large body of "informed" opinion.

The most it came to criticism was to say that some aspects could have been handled better. Now, that's not good enough frankly. One of the points of this Inquiry, one of the aims of this Inquiry has to be, and is clear from the terms of reference, to look at accountability, to look at blame, to look at calling people, who are responsible, out for the responsibility. That's what justice requires.

One other major aspect of the Inquiry, as we know from yesterday, is being heard, is catharsis, is actually, for once, being listened to, for your individual stories to be there and at last the subject of other people's attention, that you are no longer in the shadows.

I have to say that from yesterday's commemoration service and the words spoken that I think very much I can see that is central in the way that this Inquiry is going to proceed.

There is also the issue of learning from events. Clearly. Those whom I represent wish, are entitled,

have a right to know why this all happened to them. They want to ensure that this or anything like it should never happen again. They want to know what ought to have happened and, as I say, those whom I represent do not want doctors and other professionals to excuse their actions or hide behind the support of colleagues on the claim basis that they were just doing what accepted professional practice was at the time. Learning from events means applying the standards of today. In so doing one can perhaps begin to rebuild confidence, the confidence which so many of you have discovered to have been misplaced. That confidence has to be rebuilt.

One of the issues which was raised yesterday, of particular resonance for those whom I represent in coming to this issue of confidence, was the need or the failure on the part of the Scottish government to participate in the Inquiry as a core participant.

As I say, we have found the Penrose Inquiry to be a lost opportunity and unfinished business, and it is against that background that we share the concerns which were expressed by counsel to the Inquiry at the failure of the Scottish government to apply to come in as a core participant. We discussed it yesterday, some strong words were used about that. Some people whom I represent, the 250 or so Scots, talked about

cowardice. They talked about showing an appalling attitude, a shocking misjudgement and an embarrassing failure on the part of the Scottish Government, particularly when so many Scots, or people from Scotland, are core participants here. 250 is actually disproportionately large, particularly given the clear and express dissatisfaction with the Penrose process and the Penrose result. Particularly against a background that, as we understand it, it was stated by the previous Scottish health minister that the Scottish Government were going to be coming in on this Inquiry and now they seemed to have changed their mind, and we don't know why. We formally call on the Scottish Government to reconsider its attitude to the Inquiry, and recognise its worth and importance to so many of us across these islands and come and join it as a core participant. There is much left that the Scottish Government, as with all the other governments represented and administrations, can learn.

As I say, this matter is not something which is confined to the past. Some unfortunate events happening in the 1970s and 80s, before we ever had devolution, so what concern is it?

The blood contamination disaster continues to be lived and experienced by all of you who are the

survivors of it. So, it is not just about how you were treated in the past. It is about how you are treated today. As part of the recommendations we will be asking this Inquiry to come up with is making, for example, available packages of financial assistance which fully recompense individuals and families for the losses they have suffered. We will be asking for the establishment of proactive medical and nursing services, staffed by health professionals fully trained in all the conditions associated with the contamination for the care of the physical health of the survivors. We will be asking for the provision of dedicated, ongoing support services for the promotion of the emotional and social wellbeing and the protection of the mental health of the survivors because that, the toll that has taken, has not been fully recognised.

And all those are matters which will concern the Scottish Government and, therefore, that is why we think it should be here.

We heard yesterday, for the first time, that there are two current ongoing police investigations in Scotland of which we know nothing. It would be nice, actually, if we were kept informed. So, come and join us.

The terms of reference in this Inquiry were referred

to by the Chair, yesterday, as having been -- and by counsel to the Inquiry as having been drawn up after consultation with so many of the infected and affected, and we endorse them. We think that those terms of reference are all that we would wish. So, we are thankful that we have been listened to on that.

Those terms of references are big issues, but none of them should be lost. They are all in there for a reason and we want them all to be fully and comprehensively covered and looked at.

As I say, one of the issues is cover up, which wasn't looked at all in Penrose. There are issues about not just the destruction of medical and governmental records, the failure to heed legitimate calls for an independent Inquiry, but also restrictions on press investigation and reporting, and the use of Crown immunity to prevent investigation of domestic manufacturing processes.

One thing we say that the Inquiry should be careful of is not, indeed, also to be blinded by or mired in the science of all this. It can get very easy to be caught up in this as a fascinating issue of responses to unknown viruses and the like. It is always to be remembered that what happened disastrously affected real people.

One cannot, and should not, differentiate between the purely scientific and the pastoral, what happened to patients.

One has to apply, we say, a sceptical, investigative, inquisitorial approach to some of the issues which might be claimed, in terms of "well, it was just what was known" or "practice at the time". For example, risks were known about the possibility of blood borne infection from pooled products well before the emergence of either Non-A or Non-B Hepatitis or what was then called the HTLV-3, which was subsequently HIV. The Inquiry, therefore, has to, we say, look at the historical context in which therapeutic and political decisions were made.

We say there should be a need, always, to see things from the patient's perspective. We say that in producing and using its products the patients should have been at the forefront of NHS decision-making throughout. If ever they were not, that requires to be uncovered. We say that patients should have been and should be informed of their opinions, of their options, and that should count. If that didn't happen, that requires to be stated.

We have heard from so many that people were simply not advised about the risks of the blood or the blood

products which they were given. The consent wasn't even thought relevant. There was not informed consent. There was no consent, in some ways. Those are issues which this Inquiry must look at.

The attitude towards patients as people whose consent isn't really required because they are simply the subjects of this therapy also extended to the failure to inform patients that they were being tested and monitored for the evidence and development of infection. Many were not told that they had become infected, even when it was with viruses whose transmission pathways were already known. Far from putting their right to know at the forefront, it wasn't even considered to exist. That has to be tackled with by this Inquiry. There has to be a need to counter medical complacency. Why was blood sourced and injected into patients, and blood products that were taken from foreign, paid donors? For example, a whole series of boys with haemophilia, who were being treated at Yorkhill Hospital, in Glasgow, and so many of them developed HIV.

Why were local hospitals and individual consultants allowed to continue with treatments long after they had been abandoned in other parts of the country because in those other parts of the country the risks they posed

were thought to be unacceptable? Why did doctors using whole blood for transfusion appear to know so little about the risks inherent in the products which had been provided, when it seemed to be common knowledge among the transfusionists, they knew that what was being supplied was infected?

And why were patients who had not received treatment before not afforded the opportunity to benefit from developments in other parts of the country in relation to viral inactivation. In some parts of the country, heat treatment was brought in, in terms of blood and blood products, but it wasn't done uniformly. So, it meant that some were exposed to unsafe blood and unsafe blood products when there was a known method of making them safer, if not completely safe. Why did that happen?

That comes down to the need for communication. The issue of lack of communication has been central to the experience of so many whom I represent. Lack of communication between clinicians and parents and patients and their family, lack of communication between the government and the medical profession, as well as between different branches of the profession, between haematologists and those responsible for transfusions in different regional centres and local hospitals. Lack of

communication between the agencies in different parts of the United Kingdom, and lack of communication between professionals with a developed interest in blood and blood products.

Clearly, the consequences for those infected and affected has to be understood. The financial consequences are important; they cannot be a gainsaid, they cannot be simply sidelined. The financial consequences, which have been suffered, have not been compensated for, have not been recognised and, insofar as have been recognised, derisory sums have been awarded.

Even talking about money is thought to be not quite right. There is a recording that was taken as part of an oral history project curated by the Royal College of Physicians into the early days of the AIDS epidemic. There is a recording there of one former consultant haematologist making the following remarks:

"I mean, cynically, I think the patients, the few patients who are driving this are probably after money, actually."

Those remarks are symptomatic, frankly, of a disgraceful attitude taken by a number of medics, who see those -- like those whom I represent, who are seeking answers, who want redress -- as simply being

ungrateful for what was done to them, and who would now seek to blame them and continue to stigmatise them because they want to call their doctors to account. That is the kind of attitude which needs to be called out and condemned by this Inquiry.

We've got a number of procedural experiences from Penrose and expectations we think we can help in how the Inquiry might be run. One has to be realistic about what those procedural expectations are, but we just want to set out a few of those.

The first one is, as I have said, those whom I represent are participants, are Core Participants, they are not going to be sidelined again. They are not going to be silenced, they are not going to be ignored.

Many of them -- many of them are here -- have spent years understanding this phenomenon. They are phenomenal experts. That expertise needs to be called upon by this Inquiry. They know so much more. They have lived through this for so many years. Their voices, their expertise, they are willing to give that to this Inquiry. This Inquiry should take advantage of that.

Then there is the role of the lawyers. I have been tasked, I have got the honour of representing these 250 people primarily from Scotland. I've got work to do for

them. They have asked me, and those lawyers with me, Kirsten and Jamie and the Thompsons team, to ensure that, as I say, this Inquiry fulfils those expectations and that I am asked, we are asked, to call it to account. We need to be able to do our work. We want to help the Inquiry. We want to assist with counsel to the Inquiry. What we don't want is simply, again, to be treated as sitting passively there and just listening to matters for 40 hours in a week in Inquiries, or 60 hours, and doing nothing and not contributing.

This Inquiry, if it is to work, if it has to maintain the faith which has been invested in it, has to allow for an active and collaborative approach from the infected and affected through the lawyers who have come here.

So we are aware of our responsibilities. We are not here, as the lawyers, to simply be out here to make as much money out of this as we can because that's the kind of accusation which is sometimes pressed. We are aware of our responsibilities to the public purse. We will do such work as we need to, as we think is responsible and necessary to further our clients' interests, and we expect those judgments to be respected by the Inquiry.

Because the essential part is maintaining the trust and confidence of the infected and affected. This

Inquiry's efforts will come to nought unless it maintains that trust and confidence. So, those whom I represent and the way in which I represent them, we have to feel we are getting a fair crack of the whip; that our designation as Core Participants is not some nice gesture, an exercise in tokenism. This is their Inquiry. They want it to work. They want it to succeed. We want to work with it.

So as I say, we are Core Participants, we are not passive spectators, we are not officious bystanders. We are here to work with you.

As part of that, one of the issues which arose, really, from the Penrose Inquiry at some point, an awful lot of documentation was disclosed, but it was disclosed at very, very short notice, which meant, again, that although they could say, "Well, you have got all the documents". If you get them two days before the hearing begins, then you are not really getting much active participation. So, the procedure which is adopted clearly has to allow for proper time, proper consideration with our clients, all of the information as it is uncovered, because there will be lines that we wish to push and run for, and we need the proper time to find those and to substantiate them and push them. I am heartened to hear from the counsel to the Inquiry that

there will be a very much proactive approach on those issues, those practical issues.

Clearly the structuring of topics will come up, and we will be feeding in the Inquiry on that issue.

One of the points we think which may be raised in future is the possibility of examination of witnesses directly by or on behalf of the Core Participants. It may be there are questions which counsel to the Inquiry thinks, "Oh well, we don't need to ask those", but if we are going to maintain the trust and confidence of the Core Participants, if their lawyers think they're worth asking, then let us ask them.

We want witnesses to be put on oath. All witnesses, I think, really. It is not that some witnesses can just come here and give an account which they can be comfortable with. Everyone, as a matter of course, so that this evidence is compellable and on oath.

We want transparency. On one of the issues which has arisen, a practical issue, is this issue about expert panels. We can understand the idea of expert panels. There is an awful lot of technical matters, a myriad of them which will require, as it were, you, Sir, having to, as it were, learn an awful lot and we can absolutely understand the idea that experts assisting you in a teach in, a tutorial and the like, is a great

way of doing that, but we still want to be involved in that.

One of the things which you have said is that the reports of the groups will be fully open and accessible, and where there are significant disagreements among the experts on the panel they will be tested and challenged openly in the public hearings.

But one of the things that has been raised with me is what if there is a consensus amongst the experts and the received wisdom is not one which our clients, in their expertise and knowledge, think to be well founded.

Part of the issue is that we have always been fobbed off with a complacency of experts: this is how we do it, who are you to question us?

So, we can see the advantages of expert panels. We can see we think it is a good idea that we get to suggest those who might be appointed. We hope, also, that if there are concerns about some of those who are appointed, that we can raise those and they might be listened to.

What about the future?

There are a number of issues which we say this Inquiry should seek to establish as part of learning from the infected and affected experience. As you say, this has to be an opportunity for truth and justice for

the infected and affected. Maybe, but just maybe, the possibility of some kind of reconciliation between those responsible for the infections, both from the NHS and government and those who have suffered. That needs an apology. That needs an acceptance of responsibility. Thus far, certainly post-penrose, we have seen no signs of contrition or regret from the medical establishment or individuals who have come to that Inquiry.

Various lessons clearly have to be learned for the future. One of them is stating the obvious, no blood from prisoners. No paid-for blood. There's always a temptation to source blood and/or blood products in the most economically efficient way possible, but that should not allow for a compromise in safety. Safety has to come first.

Part of that, we say, part of our recommendations, which we will be arguing for, is that positively there might be a safety -- that this Inquiry might recommend that a safety levy be imposed on the large pharmaceutical companies, because companies which introduce new products and treatments in a sense benefit, they profit from that if they work. But when they don't work, the cost of that falls on the population as a whole. Those who profit from treatments should be ready to pay for the failures in those

treatments. So, therefore, we say it would be appropriate that some kind of hypothecated levy be taken as part of the profits of pharmaceutical companies to set up a fund which can be called upon should ever anything of this sort happen and can be called upon by those who have already suffered.

A duty of candour. It is already now been brought into the law. There have been changes in legislation to ensure that medical professionals actually involve and say and state, at an early stage, potential risks or problems with treatments past, current or future are identified. We require full patient involvement.

Now, all those good standards have come in very, very recently in Scotland, only enforced the duty of candour. Regulations came into force only on 1 April of this year. But it is important, I think, that legal duty become a reality and that the recommendations focus on that because so much of the anger has been because of the lack of candour, the unwillingness to just tell people what's happening.

So that is incredibly important. The security and reliability of medical records. I have said often enough that, in so many cases, it appears that medical records have been redacted by persons unknown and important information has gone. But, also, false

information has been added. In so many cases where part of this culture of blaming the infected and affected, the suggestions have sometimes come, in those medical records which have been recovered, that this person must be an intravenous drug user or a secret alcoholic because they are just not owning up to these issues. Those are false. That has to be taken out. So, those aspects, in terms of medical records, their security and their accuracy are issues which are very much at the forefront.

Being informed and getting consent about being the subject of medical research studies. We know there are changes in the law with that, but it is important they be underlined because one of the attitudes has been that the infected have been objects of anonymous study and they have not been told. Their lives have become data sets to be mined, and they didn't know about it, and that's a violation.

There were two brothers, at one of the meetings I was at, who said that they were haemophiliacs, young boys having to come in after having been infected, but not knowing of their infection, but being the subject of a study. The doctor referred to them as "there's my young PUPs". They thought it was a term of affection. They thought it was because he liked them. They didn't

know it was an acronym for Previously Uninfected Patients. That kind of attitude, once again that lack of respect, that lack of understanding of patients, integrity of patients, individuals, 'stop classifying me as a subject of your attention. Treat me as an equal. Tell me the truth'.

Caring for the infected and affected. There has got to be follow up. There has got to be long-term follow up by those who have been infected and affected. This is not something which happened once and then can be forgotten and closed off. There are continuing consequences. There is a need for psychosocial support. There is a need, as we said, for full compensation. Full compensation is awarded in Ireland. If it can be done in Ireland, surely, surely we can do it here.

We say there should be a lifting of time bars on court actions. That could be part of an issue in relation to the full funding which should be set up. If we can't agree on full funding, then we should be able to at least have the option of opening court actions. There should be a secure stream for funding for the charities who have done such sterling work and have kept this issue alive, and the fact that we are all here is tribute to the work which they did. They have to be supported.

There's got to be recommendations about further medical research. We believe that the Inquiry will cover many areas where further medical research is required to understand fully the implications of the contaminated blood disaster for victims. We say that the UK Government should establish a research fund to support work in these areas. For example, are there any clinical implications of being repeatedly infected by different genotypes of Hepatitis C or does multiple exposure have an impact on clearing the virus with the immune response fatigue? And do the long-term sexual partners of people with an inherited bleeding disorder who have been exposed to contaminated blood or blood products, do they have an elevated rate of any particular conditions? Those are matters which have yet to be uncovered, have to be researched into, but we have our suspicions. These are not simply unfounded issues.

So, in conclusion, the 250 or so individuals who have asked me and the Thompsons team, and Jamie and Kirsten to represent them, we have entered this Inquiry process with confidence that it can and the hope that it will deliver on the terms of reference and meet the objectives, which are detailed in that statement. The Inquiry has got to be about the infected and affected whom we represent, and others from around the country.

They are the people who have to be at the heart of this process in any meaningful way. They are committed. We, as their legal representatives, are committed to working with the Inquiry, to ensure that it reaches a positive outcome, where so many other investigations, bodies and inquiries have failed. That commitment is based on the legitimate and, we hope, well-founded expectation that we will find in this Inquiry the investigation, the respect, the trust and the fearless honesty, which was lacking in so much of our experience to date with other bodies.

So can I commend you, Sir, for your opening remarks in which you celebrated the fundamental dignity, the perseverance, the sheer courage of the infected and affected.

What we have seen to date has given those whom I represent hope and a cautious optimism, which is as much optimism as you are likely to get from Scots.

So, we look forward to working with the Inquiry in a fully collaborative and active way, with a view to achieving our common objectives of fulfilling the terms of reference, bringing justice to those who have died and to those whose lives have been unutterably altered and burdened by this scandal.

It is to those lost lives, to those stolen lives

that we commit ourselves. Thank you.
SIR BRIAN LANGSTAFF: Having myself grown up in Scotland, I feel honoured to be the recipient of cautious optimism.
Can I just say, in some response, that I believe, as Mr O'Neill has said, that core participant contains two words, the second of which is "participant" and I look forward to all core participants playing a full and contributive part in this Inquiry.
Our second speaker is the first unrepresented core participant, Della Ryness-Hirsch.
Opening statement by DELLA RYNESS-HIRSCH
MS HIRSCH: I'll introduce myself, first. My name is Della Ryness-Hirsch. My husband, Dan, and I had twin sons in 1976, one of whom was diagnosed with haemophilia.
Dan and I had met in San Francisco, where I was living in the 60s. I mention this because it will have significance later on in the Inquiry when I give my evidence, but I feel overwhelmed and somewhat disbelieving that after all these long years of struggle and heartache we, the devastated community, are to finally be able to tell, in public, before a judge and his advisers, the absolutely unbelievably terrible story of contaminated blood products.

Some of the wider world might only think of blood products being just for those with haemophilia, like our son, who died at the age of 35, leaving a loving partner of 12 years and their baby of 10 months old. But, as we all know now, contaminated products find their way outside that cohort and manage to kill that young mother having her first baby and needing a small transfusion, that road accident victim run over by some careless speeding driver. Those women having relationships with their husbands or partners, and all the myriad ways that other people became infected.
I was so moved to see, yesterday, the wonderful expression of all that has happened in our community that had been put together by the committee. It chose through film and music and speech, and wonderful photos, including one of our son, the truly horrendous role that has been visited on us.
So, how did this all happen and when did the medical profession know, and what made them continue to use these products for many years after contamination was both suspected and realised?
I was asked to comment on the Inquiry's terms of reference and now, having read and re-read these terms that they have put together, I would say that they do cover many of the areas about which we would all like to

know more. One area that definitely needs a stronger and harder light shone on it, mentioned by the previous speaker, is exactly why so many in the medical and ADDI professions not only did not share their suspicions, but not even when they had real knowledge of what was happening, but at the same time made it impossible for any of their clients, us, to ask questions or raise doubts.
It is now quite clear that many doctors and others involved in the medical field did know that the treatment they were using was suspect. In my local paper, I live in London, in Highgate, the Ham & High, last week the front page was completely given over to an article about a well-known professor, head of a haemophilia centre, stating that she knew, and I quote, that:
"Everyone in her haemophilia unit would get Hepatitis C."
That will come back later in my evidence because I had quite a lot of interaction there.
Whilst another haemophilia centre head, talking on a panel on radio 4 some months ago that Dan and I were listening to, became irate when being challenged on this subject. So, it would be my suggestion that had both the medical profession and all of the others and here we

might mention the Department of Health who were involved in blood product treatment, were engaged in what I call a complicity of silence and, therefore, did not call out their suspicions and their anxieties about this for years and this led, I believe, to the long, long delay in looking for new ways to produce safe alternatives.
We also cannot forget that looming over the entire world of blood was the Department of Health. The one area of government that were directly and, even more worrying, still is responsible for the nation's health. We have all heard the stories about the destruction of documents and more and more than that, but stories -- no, sorry, and now with our Inquiry launched under the auspices of the cabinet office, and not the Department of Health, we, the community of the affected and infected can finally hope to see our Inquiry quietly but firmly look into all the Department of Health's dark corners.
I contend that all of these that I have just named, had they been called out by discussing suspicions about their treatment, I would suggest that this would have caused such an uproar at the time and this in turn would have hit the drug companies' bottom line, otherwise known as their profitability, which certainly gives sufficient motivation for the companies, researchers and

the DoH to have started rapidly working at top speed on what might have been done about it and heat treated products would have been available in a short time followed by a recombinant Factor 8. I want to point out that in fact this is exactly what happened eventually, when various television programmes covering the blood contamination were shown years later and the public were finally alerted to it. Newspapers had leaders about it, television continued to publicise it and, within a short time, unbelievably, there was heat treatment followed shortly by recombinant.

So, that silence screwed us.

The adage, necessity is the mother of invention, springs to mind. I do believe by lying and keeping this truth from the community we were denied the possibility of safe treatment years earlier. I suggest that this would be an area which the Inquiry address in some detail.

We were often made -- the people who were affected that is -- to feel that in some way we were to blame. They would hear no word of warning and we, who did know something was happening, were treated as pariahs: I'm the doctor and, if I think it's okay, it is okay.

As the diseases and ill health persisted, and people became even sicker with new terrors heaped upon them --

and I can testify this because it happened to our son several times -- there seemed to be a standard procedure of whipping some poor sod off from the waiting area at the haemophilia centres and breezily telling them that they had been exposed to yet another horrifying disease, and then sending them off into the night sadly not whistling a cheery song.

Two other important areas in which the Inquiry have already said they wish to look more closely, which I totally endorse, are the Haemophilia Society, who my husband and I have supported financially ever since our son was born, even when they refused when called upon to stand up and fight for the affected community, telling me, "We really only deal with newly diagnosed and young children".

They resisted that call. Perhaps even more terribly, the terrible trusts that were created to help the afflicted community. The misery and the appalling lack of care or even of interest in the disaster that was unfolding can never be overstated. I myself was appalled when I was dealing with them on behalf of my son's family. They were chaotic, they were offensive. Certainly talking to me they referred to any financial assistance as "charity". Charity! This was so appalling that I took it further and will give evidence

of this at the appropriate time.

At the time of these conversations, our son had been dead for three weeks, so that is an area which I cannot emphasise more strongly. Their trustees turned up perhaps once a month. So, if you called in, in desperate need, you often had to wait until the next trustee was due, next month, to sign the necessary papers. Their website pages were of such poor quality that if there was any information it was incomprehensible. I have had my own experiences with them and have heard of many more who have suffered even worse treatment than they had meted out on this already decimated community. They needed a very bright light indeed shone upon them.

This is what I say to you: this is our Inquiry. This is where we get to ask all those questions that we were not allowed to get out of our mouths and where under the careful gaze of the Inquiry they will finally have to be answered.

As I said at the beginning of this speech, we, the affected community, acquired these infections via very many different means and when, at a recent meeting at the Inquiry headquarters, I came to understand that there was a tremendous discord amongst many different groups of people who had become infected in many

different ways: transfusions; haemophiliacs; sexual activity. There was bad feeling and I found it distressing.

I have worked alone since my son was diagnosed with haemophilia in 1976, a few weeks after he was born. There had been no haemophilia in our family, so we had no advice or knowledge in-house as they say. Right back then I saw a terrible disconnect between the groups representing haemophiliacs and those who acquired a HIV or Hep C via other routes.

I therefore would like to repeat what I said at the beginning and what I said earlier, that I see no difference. All had been infected through blood that was known to be contaminated by the very doctors and authorities who were supposed to be looking after us.

Dying, as our son did, is dying whatever the method of infection. Living a sick life as an infected person is horrible enough without those infected by a different route driving wedges between us. So, as I said at the beginning of the speech, it was so wonderful and healing to see how inclusive the film and the opening was yesterday, and I do hope that all of those divisions are gone. Instead of all of us so destroyed by what happened fighting each other, we can work together with this terrific Inquiry team we have been given, to bring

justice to the entire community.
Before I end my speech, I do want to bring forward those who have stood so firmly on my side and on the side of those seeking truth and justice to this affected community of ours.
I want to thank Diana Johnson and Sir Peter Bottomley and all those who proceeded them on the APPG for contaminated blood. Over the years, they all kept going, fighting for justice on our behalf, doggedly and determinedly. Our local MP, Catherine West, has remained interested and concerned about the wrongs that have been visited on us.
I especially want to mention my friend, Lynne Kelly, head of Haemophilia Wales, who I met years ago at a Department of Health board that I was on, where we had a meeting with the heads of the haemophilia units. They had asked her to give a talk about the fact that the affected community in Wales had collected enough money to buy a fibroscan, but did not have enough money to fund a technician who could work it and analyse the results. She gave a brilliantly clear exposition on this subject, and when she sat down, no one thanked her. They hardly had listened. They immediately, the haemophilia chiefs, started arguing between themselves about their funding.

I resigned from the committee, found out who she was, got in touch and, in the years since, she has been my friend and my guide into all things haemophilia.
Most of all I want to call out my sister, Baroness Lynne Featherstone, my younger sister, you must understand, who has supported and helped not just me, but those in our community who approached her for help, with an energy and understanding that was able to take us further and in more depth than we could have imagined.
Finally, to my husband, Dan, who listened to me recite this speech and changed it ten times at least, and not particularly patiently, but with an attention and a care shared and a love of me and our family.
So, finally, against the odds, we have an Inquiry with a judge and a team who are totally committed to bringing out all the truths and untruths of this terrible tragedy. Thanks, guys.
SIR BRIAN LANGSTAFF: We'll take a 20 minute break. Be back, please, at 11.40.
(11.20 am)
(A short break)
(11.40 am)
SIR BRIAN LANGSTAFF: David Lock QC on behalf of the core participants represented by Leigh Day & Co.

Opening statement by DAVID LOCK
MR LOCK: Thank you very much, Sir Brian.
Ladies and gentlemen, I don't have very much voice thanks to the ravages of a cold, so I will do my best. I have the privilege -- and it is an enormous privilege -- of being instructed by Leigh Day, together with my learned friend, Ms Hannah Gibbs on behalf of 251 victims of the infected blood scandal. Many of our clients are active members of the contaminated blood campaign, CBC, and Leigh Day have given pro bono legal assistance to the CBC for about the past four years. We have been involved in a series of challenges to the chaotic and ad hoc ex gratia payment schemes and, along with a number of other people, have been responsible for the challenges which led to the present changes -- not enough change, but at least some change -- to the schemes.
The one thing which links all our clients is that they are or are related to individuals who became infected with Hepatitis C or HCV as a result of NHS contaminated blood or contaminated blood products.
Despite this unifying feature, every one of our clients has suffered in different ways for different reasons; that is a reflection of the devastatingly large reach of the contaminated blood scandal.

Some of our clients contracted Hepatitis C and continue to carry the virus, and they have developed very significant physical, psychological and cognitive disabilities as a result of carrying the virus in their bodies for decades.
Others contracted Hepatitis C and, after undergoing one of a number of deeply unpleasant and painful treatments over a period of many months, have been cleared of the virus. The fact that the virus is no longer detectable in their bodies does not signify an end to their suffering.
Many of these individuals developed very significant disabilities as a result of carrying the virus. Medical treatment may have cleared the virus from their bodies, but they have been left with the permanent, significant physical, psychological and cognitive disabilities.
Some of our clients are relatives of victims who contracted the Hepatitis C virus from NHS contaminated blood or blood products, many of whom are now deceased. In all cases, the relatives have seen their loved ones suffering significant disabilities and developing serious conditions, which in many cases led to a painful and distressing death.
Some of our clients are co-infected because they carry the HIV virus as well as Hepatitis C, or they are

relatives of people who are or were co-infected.
It is important to emphasise that the impact of the infected blood scandal on many of our clients is not limited to HIV and Hepatitis C. They have been exposed to a wide range of other diseases and receive warning letters which suggest they may carry dormant pathogens for which there is no test, such as new variant CJD. For those who are not familiar with this disease, new variant CJD is a prion disease for which there is no cure. There is strong evidence that it is caused by the same agent that led to the outbreak of mad cow disease. Many of you will remember the utter shock when it was discovered that mad cow disease was affecting humans and the climate of fear associated with beef products.
The worry that those who ate beef might develop symptoms of this incurable and terrifying disease was widespread, but thankfully few in the general population have shown signs of the condition. But, in contrast, the real risk of developing CJD is something our clients have to live with every day.
The continuing psychological impact of these unknown risks is difficult to overestimate. So is the distress caused to our clients by the need to explain, every time one of them visits a hospital or a dentist, that there is a risk of transmission.

We strongly welcome the fact this Inquiry recognises the victims are not limited to those who were infected with the viruses, the result of NHS contaminated blood or blood products. All our clients live in families, they all live in communities. The impact of this disaster has spread through families and communities.
Poetry was used to great effect in the commemoration yesterday, but my clients have asked me to refer to another poet, to John Donne, whose words famously set out how they feel. He said:
"No man is an island, entire of itself; every man is a piece of the Continent, a part of the main. If a clod be washed away by the sea, Europe is the less, as well as if a promontory were, as well as any manor of thy friend's or of thine own were: any man's death diminishes me, because I am involved in mankind, and therefore never send to know for whom the bells tolls; it tolls for thee."
The bell has tolled for many men and women, all victims of this tragedy. The victims include parents, family members, carers and friends of both the living and the dead. Some limited recognition has been given through the haphazard and grudging way the ex gratia compensation schemes have been set up, but in the main, they have only offered support directly to the affected

victims.
My clients ask this Inquiry to be the first occasion on which there is formal recognition of the devastating impact this disaster has had on parents who have seen their children suffer terrible disabilities or die at far too early an age, or those devoted spouses and carers whose entire lives have been shared by their commitment to a victim.
We thus welcome the recognition the Inquiry offers in its focus on all those whose lives have been affected by these terrible events, only some of whom are actually infected.
We also welcome the fact the government has finally agreed to set up this formal public Inquiry, and our clients are determined to do everything they can to assist you, Sir Brian, as Chairman of the Inquiry, and your staff, to undertake the almost impossible job of peeling away the obfuscation, the delay and the denial, which has characterised the official response to this tragedy over the past three decades.
There are a series of specific points our clients want me to make on their behalf, and I am delighted to do so.
First of all, the terms of reference. Our clients want to welcome the width of the terms of reference, but

they also welcome the fact that the terms of reference for the Inquiry were agreed following a wide-ranging consultation. They are grateful they have their voice heard in setting the terms of reference.
You will expect our clients to be rigorous in ensuring that you investigate comprehensively across the whole range of issues raised by your terms of reference.
Now, we understand the need for expedition, but we have very clear instructions that full respect is given to the width of the terms of reference and no attempt is made to cut them down for administrative convenience or to spare the embarrassment of those whose administrative decision means they are discovered to be key players in the sequence of events that led to the tragedy.
That brings me to the second point, that the victims I have the privilege of representing wish to raise. That is: how should the Inquiry approach individuals who have been involved in these events, but can no longer defend their action?
Many individuals who are key decision-makers will no longer be able to defend their own reputations because they are deceased, long retired, or have no memory of the relevant events. We appreciate there will be an enormous temptation to protect the reputations of those who cannot speak for themselves because they're

deceased, because they're living in retirement, because they cannot be expected to recall events of many, many years ago. Our clients do not want this Inquiry to turn into a witch-hunt.

But the evidence is likely to show reckless, uncaring, incompetent or wholly inappropriate behaviour by NHS and government decision makers. We invite the Inquiry to follow the evidence chain wherever it leads. The Inquiry process should not hold back from investigating what really went on, what decisions were made, what risks were ignored, what errors were committed, even though this may result in reaching some difficult, unpalatable or appalling conclusions, which will affect the reputations of individual civil servants, ministers, doctors or NHS officials.

The reason for that is that public officials working for public bodies, whether in government, the NHS or elsewhere in the public services, must be held publicly accountable for what they did or did not do.

My clients fully accept any judgment must be based upon the information available to a decision maker at the time, but legitimate questions we think should be asked about what the individuals knew, what inquiries he or she made to establish the truth about the risks or benefits of a course of action and what he or she ought

to have known before making key decisions.

We hope this Inquiry will not refrain from holding public servants properly to account for their acts and omissions merely because the individual is deceased or cannot now recall the circumstances which led to the decision in question.

We accept there will be a fine line to tread between appropriate respect for those who cannot speak for themselves, and proper transparency and accountability. But, in treading that line, we urge the Inquiry to bear in mind that every employee of a government body knows, and has always known, that he or she will be called to account for the discharge of his or her public functions at an undefined date in the future. The function this Inquiry will be undertaking, of scrutinising decision-making of public bodies carried out by individuals, is one that all public officials know is possible because public officials are accountable to the public for their actions, just as they are paid by the public for their services.

Accordingly, whilst we are always seeking to be fair to protect the reputations of those who cannot speak for themselves, we expect the Inquiry to be rigorous in exploring precisely how the decisions were made by named individuals which led to the thousands of deaths of

wholly innocent NHS patients, and how the lives of so many others came to be permanently blighted by serious physical, psychological and cognitive disabilities, and in the balance of interests between transparency and the protection of reputations, we expect no stone to be left unturned however much unturning that stone reveals events which demonstrate incompetence, a lack of understanding, inadequate inquiry before decisions were made, shortcomings as a result of resource constraints, plain incompetence or worse.

Now, my clients respect the inquisitorial nature of this Inquiry. We won't seek to routinely cross-examine any witnesses. We may suggest questions to be put by counsel to the Inquiry, but we accept for most cases the choice of questions must be a matter for the Inquiry team to decide.

There will be a small number of critical witnesses where we will be inviting the Inquiry to take a different course. Where a key senior decision-maker is giving evidence, we will be inviting the Chair to accept that our clients will want to hear that senior decision-maker answering their questions, put by their chosen representative.

Next, I need to say something about disclosure.

On 29 March 1991, the inquests into the deaths of

96 football fans, who died at Hillsborough returned a verdict of accidental death. That judicial process was in part informed by the outcome of a report by Lord Justice Taylor into the tragedy. Those two processes were both utterly inadequate to get to the truth of what happened at Hillsborough, primarily because of inadequate disclosure of the records made at the time by all the relevant individuals who had a part to play in the events, the tragic events of 29 March 1989.

The lack of disclosure did not stop there. On 5 November 1993, the divisional court refused an application for judicial review of the inquest verdicts.

On 13 February 1998, Lord Justice Stuart-Smith reviewed new evidence in relation to the tragedy at Hillsborough and recommended no action should be taken to reopen the inquests or commence investigations into possible prosecution of individuals whose decisions may have led to those deaths.

Those who were closely involved with the events knew that the official account was far from the truth. They knew the real story of events, which happened at Hillsborough, had not yet been told. The families of the 96 knew the truth had not been told, and they were a thorn in the side of the establishment for year after

year as they made what seemed impossible demands to reopen findings made in an official report, in inquest and in a judicial investigation, but -- and this is the chilling lesson we invite this Inquiry to focus on -- the families were repeatedly right and the establishment was repeatedly wrong.

The families campaigning eventually persuaded the government to set up the Hillsborough Panel. That panel examined 450,000 documents in their quest to find the truth. Personal records by former police officers were obtained from lofts up and down the country. Legal professional privilege was set aside in the interests of finding the truth. Official documents were discovered for the first time, and they painted a very different picture to the story that had been told to Lord Justice Taylor, to the inquest and to Lord Justice Stuart-Smith.

Eventually, on 12 September 2012, the Hillsborough Panel published its report, properly informed by a vast number of previously undisclosed documents. That led to new inquests, which in turn led to the findings handed down by the jury on 26 April 2016, that 96 Liverpool fans were unlawfully killed.

My clients are entitled to believe there are lessons that this Inquiry can learn from the Hillsborough

process.

Now, very considerable credit needs to be given to the late Lord Archer of Sandwell, the former solicitor general, who chaired the non-statutory inquiry into the infected blood scandal, which reported in 2009. But there is a telling phrase in the Archer report, where Sir Nigel Crisp is reported to have told Lord Jenkin, the former Secretary of State, that potentially incriminating documents relating to this disaster had been destroyed "with intent to draw a line under the disaster".

We understand there are reports that the private papers of the former Secretary of State, David Owen, were part of this destruction exercise, and that is clearly something which the Inquiry will want to investigate, to ensure that this type of exercise is never repeated by any government body, in any circumstance, at any point in the future, however convenient that might have appeared to the civil servants or the governments of the day.

If it is true that civil servants deliberately destroyed documents to draw a line under the disaster, the civil servants were the only individuals who could walk away from this disaster as a result of the deliberate act of wanton destruction of records. Our

clients were required to live with the consequences of the decisions made by public officials for the rest of their lives, and many had their lives cut short as a result of those decisions.

The reality, as you will know, Sir Brian, as your Inquiry team are trying to find out, is that a single copy of a document is a rarity in government. The nature of government is that multiple copies of any significant documents are created. They are filed in numerous different places, and not every civil servant will have considered the deliberate destruction of documents was an appropriate policy response to this disaster.

Our clients are confident it is possible to find copies of virtually all documents generated by the government in relation to this disaster, albeit it will be a painstaking, massive task. It will require persistence and ingenuity, and will require the investigators to use all the skills and techniques developed in Hillsborough and the Gosport Inquiry. We are confident that a thorough document disclosure process will assist in uncovering the whole story.

We would therefore welcome the clear statements by Jenni Richards QC, yesterday, that the Inquiry has an expectation that public bodies responding to its

requests for disclosure will waive legal professional privilege.

Legal professional privilege should not be used as a shield to prevent those who were paid by the public from being accountable to the public, in this Inquiry. We hope the government will accept, whatever the embarrassment or the potential financial cost, the time for secrecy about what went on is over. Just as legal professional privilege can be overridden in the public interest under the Freedom of Information Act, something of which you will be very well aware, legal professional privilege should not be raised to prevent the full truth being disclosed to this Inquiry.

Therefore, we hope the Department of Health, and those acting for the various NHS bodies, will put no obstacles whatsoever in the way of the Inquiry team discovering all of the relevant documents.

This Inquiry only happened because of the tireless campaigning of a number of groups, including my clients, the Contaminated Blood Campaign and many others. Now that it is set up, all public bodies should assist by providing all relevant documents, so that this final chance to discover the truth can be as much of a success as it possibly can, however awkward or embarrassing those disclosures may be.

Warnings, the fourth point. The terms of reference rightly focus on the sequence of events that led to this disaster and the information that was provided to the government that ought to have led to identification of the risks of using untested blood and blood products. Others have spoken of the need to establish precisely what public officials were told about the risks of importing contaminated blood, when those warnings were given, when they should have been given, and how the government and the NHS responded and why they delayed in acting on those warnings.

It is clear that the failure to act earlier resulted in deaths and blighted lives. So, we will support the Inquiry in vigorously investigating how blood products came to be used in the NHS and why those warnings were not heeded.

Fifthly, informed consent. The issue of informed consent lies at the very heart of any lawful medical treatment. Following the seminal judgment in Montgomery, informed consent has been established to be part of the common law, but it was always part of the common law. Montgomery did not change the law. The need for medical consent by a patient to be informed of the risks has always been present. One important aspect of the risks that my clients are particularly keen to

have investigated is the justification of treating people with bleeding disorders with massively pooled factor products. In particular, to understand the nature of the risks faced by those with severe, moderate or mild bleeding disorders, because the Inquiry needs to discover why NHS patients were exposed to the risk of contracting viruses from contaminated blood and whether they were given proper information about the risks they were running. Particularly, why they were exposed to those risks when there was no immediate or urgent need for the application of blood products.

Some of my clients were affected as a result of regular prophylactic treatment that was meant to be preventative of future ill-health, but in fact became causative of devastating disabilities. The extent to which these patients had the risk of such prophylactic treatment explained to them, or not explained to them, is plainly an area for this Inquiry to examine.

Sixthly, the source of the infected blood products. There has been an assumption in some of the literature that all the NHS infected blood came from abroad, typically from US-based prisoners or those on the margins of society. However, it will be part of this Inquiry to determine whether that is a largely correct picture or is a convenient myth.

The extent to which inadequacies in our own domestic NHS blood collection service led to NHS contaminated blood or blood products will be a very important area for this Inquiry.

Seventh, disclosure to infected patients. This Inquiry will wish to investigate why patients were not told about their infections, even when this knowledge was held by doctors. The evidence will show some patients had to wait many years before their diagnosis was confirmed, putting them and their loved ones and members of their families at risk. Whether and, if so, why there was any systematic monitoring of patients with infections must be vigorously investigated. In particular, was there monitoring of patients who were infected by the NHS without the knowledge or consent of those patients.

That brings us directly to the next point my clients want you to investigate. The attempt to deflect blame from the NHS.

The Inquiry will want to know why so many infected patients were accused of having acquired the viruses by drug taking, alcoholism, sexual promiscuity or any number of other potential reasons. The experience of my clients is the NHS was often keen to find any cause as to why individual patients carried the Hepatitis C

virus, rather than admitting the individual contracted the virus from NHS contaminated blood.

Those accusations appear to my clients to have been made on a systematic basis, regardless of the supporting evidence in an individual case, and the damage of victim blaming cannot be underestimated.

Next, treatment regimes. We support the Inquiry examining whether victims have received the right treatments, particularly as those treatments have developed from research into clinical practice. Victims whose lives were blighted by the NHS decision-making have never been prioritised for emerging curative or symptom-relieving treatments by the NHS. The argument has always been advanced: the NHS cannot prioritise the treatment of some patients who carry a virus over others who carry the same virus based on the underlying cause of the infection, but the Inquiry will have to look to determine whether that is a morally defensible position or an appropriate way for the NHS to respond. That raises profound ethical questions.

In summary, the position of my clients is they are entirely blameless for the disabilities inflicted on them by the NHS and they ought, therefore, to have been at the front of the queue for any emerging treatments.

Medical records. I was interested in what

Mr O'Neill had to say about medical records. There is an enormous concern amongst my clients about repeated patterns of the NHS losing medical records relating to patients who have been damaged by the NHS's own actions. They do not accept for a moment that this loss of medical records from these patients was unrelated to the cause of their infections. This appears to them to be a case of the NHS getting rid of the evidence of the sins of the past. But, if so, who organised it? Who made the decisions?

The Inquiry will want to look to see the extent to which this is supported in the evidence and a culture emerged of losing records which were embarrassing to the service.

Was this a series of coincidences, or was this a pattern of behaviour by NHS bodies in an attempt to limit the reputational damage to the health service?

Next, the role undertaken by other parties. The main focus of this Inquiry will undoubtedly be on individuals working for the government, ministers and senior officials for the NHS. But there are very large numbers of other bodies whose actions or omissions played a significant part in the sequence of events or influenced disproportionate, unbalanced or inappropriate responses to the tragedy.

The prioritisation of one group of victims over another may seem entirely justifiable to someone who is promoting the cause of that particular group of victims. It is easy to see, objectively, different victim groups have been treated differently, but this is utterly indefensible and is a part of the sorry history of this tragedy.

The focus, we suggest, should not be on those groups who acted for victims and who were pressing for and acting in the interests of those they represent, perfectly properly. The focus must be on government decision-makers who had a duty to all victims and, we suggest, failed to act equitably between different categories of victims.

Next, mortality rates. A very different approach is taken to different victims is perhaps illustrated best by the absence of any comprehensive analysis of different mortality rates across the different viruses caused by infected blood and infected blood products. My clients hope the Inquiry will for the first time be able to gain a full and complete picture of the mortality rate within our infected community. To do so will require a detailed analysis of the data held by the five previously separate ex gratia schemes. This information will need to be collected in a way to show

how the mortality rates of the affected community have changed over time, and there are five specific categories we would urge the Inquiry to focus on:

Co-infected patients, HCV patients at stage 2, co-infected patients at HCV stage 1, monoinfected patients at stage 2, monoinfected HCV patients at stage 1 and, of course, monoinfected HIV patients. The mortality rates will be different between those groups.

Thirteenth point, we are nearly there. Support for spouses, partners and victims. It is mystifying as to how anyone in government could have thought it was appropriate to provide financial support to spouses, partners, or children of individuals, who died as a direct result of acquiring one type of virus from NHS infected blood, but to deny a similar level of financial support to spouses, or partners, or children of individuals who died as a result of acquiring a different type of virus from the NHS.

Until very recently that was how government public money was used across the various schemes. This Inquiry will want to look to see how that utterly indefensible set of circumstances emerged and why it took so long before that obvious disparity was corrected.

Looking forward to the end. It is a sad but inevitable fact that some of my clients will not live to

see the final report produced by this Inquiry. They have already had to wait far too long, but, for some, they will never see the final outcome. There is a balance between urgency and the need to be comprehensive. We do not urge the Inquiry to restrict the scope of investigations nor to produce a report too quickly, but we equally commend the steps that have been taken to proceed with the Inquiry as expeditiously as possible. Can we invite the Inquiry now to focus on and to set the ground rules that will be taken following the end of the evidence.

My clients are particularly concerned this Inquiry should learn the lessons from other public inquiries where there have been very extensive delays, sometimes running into multiple years between the conclusion of the evidence and the publication of the final report. Some delay is inevitable and proper. Other public inquiries have been dogged by disputes, endless disputes, often mitigated in the court, where individuals seek to prevent the Inquiry reaching conclusions with which they do not agree or being subject to criticisms which they do not accept.

Now, the trigger for this post-evidence series of confidential disputes has been the practice of sending warning letters known as "Salmon Letters" or "Maxwell

Letters" to individuals whose conduct is proposed to be criticised in the final Inquiry report.

However, that process is confidential and is thus inherently unfair to the other participants who are excluded from the debate about the extent to which any individual organisation is being criticised.

Now, individuals who give evidence in a court of law do not have the opportunity to debate the merit of the judge's conclusions before the publication of a judgment. The judge discharges his or her functions by ensuring fairness within the process, but there is no requirement for an additional sequence of events before judgment is handed down.

Given the need that this report should be published as quickly as possible, and given the unfortunate experience of other public inquiries, we invite the Chair to indicate now that fairness to individuals and organisations will be discharged within the Inquiry process and not by way of warning letters sent during the writing up phase.

We accept this may, on occasion, mean the Inquiry recalling individuals to give further evidence, or organisations, the opportunity to answer criticisms which emerge at a later stage of the evidence, but that process has three advantages.

First, it's fair and gives due respect to the rights of all participants. The confidential debate and subsequent litigation arising from warning letters is unfair to other participants by the very nature of the confidential process which is being undertaken.

Secondly, not sending warning letters, perhaps save in exceptional circumstances, will speed up the process between the end of the evidence and the publication of the final report.

Thirdly, it will ensure that all relevant debate on material issues meets the high standards of transparency and accountability to which this Inquiry has rightly committed itself.

Therefore, we invite the Chair to reflect on whether this is an area where he considers to set out the ground rules at the outset of the Inquiry.

So, Mr Chairman, in summary, our clients have lived with this blight over their lives for decades. They have repeatedly knocked on the door of government to ask for answers knowing that every year that passed would make the task of finding those answers more difficult. This will be their final chance of securing truth and justice for those who are living, albeit they are still suffering profound disabilities as a result of the tragedy.

It is also the final opportunity to recognise the extent to which lives were cut short for those victims who died before they had a chance to take part.

There will always be errors in organisations as complex as the NHS, and this Inquiry has the opportunity to identify the monumental errors that were made in relation to infected blood and blood products, and to lay bare the decision-making process which failed to prioritise the interests of patients over the system and led to those errors remaining uncorrected for too many years with the disastrous consequences that everybody knows about.

The sincere hope of our clients is that future generations of NHS and government decision-makers will understand what went so tragically and repeatedly wrong in relation to NHS infected blood and blood products.

That, of course, does not guarantee that future decision-makers will not follow a similar course in future, but the legacy of a report which understands how and why things went so terribly wrong will very substantially reduce the chance of another tragedy.

So, Mr Chairman, our clients will endeavour to see this process through as a cooperative venture with everyone involved, with the focus on establishing a comprehensive account of who, how, why, when and where

decisions were made that blighted the lives of thousands and led to so many premature deaths.

We will be supportive but critical friends of the Inquiry, holding it to account and playing our part in getting to the truth before it is too late to find out the truth.

SIR BRIAN LANGSTAFF: Thank you very much, Mr Lock. Our next contributor is Michelle Tolley.

Opening statement by MICHELLE TOLLEY

MS TOLLEY: Good afternoon, everyone, Sir Brian, Inquiry team, members of the press. My name is Michelle Tolley and I am 53 years old, and I run a wonderful support group called Contaminated Whole Blood UK, which I'm very proud of.

My story. I had two blood transfusions, one in September 1987 and the second in February 1991, after childbirth. During the mid-1990s, there was some campaign that came on the TV regarding bloods that had not been screened, HIV, where you could have been infected via tattoos, dentistry, operations abroad, blood transfusions and several other methods.

I telephoned the number, received the information through and dutifully went along to see my GP at that time with my worries and concerns, as I was already feeling severe fatigue.

I went along to my GP, explained that I had severe fatigue, to which he replied, "Well, of course you have. You've got four young children, what do you expect?"

I then spoke about the adverts I'd seen on the television and my concerns that I'd had two blood transfusions before the bloods were screened. His reply to that was, "Don't be silly, of course you won't have that".

Now, when you're a young mum responsible for four children, you look at your health professional with trust that they are telling you the truth and I jollied along on my way, still very tired.

Apparently there was a look-back. A look-back exercise to try to identify those who may have been infected. Well, they didn't look very far, did they? As there are so many of us infected victims, who still do not know today that they've been given a death sentence without even committing a crime.

I was finally diagnosed in November 2015, by chance, and with a new GP, I might add, that I did in fact have Hepatitis C.

The impact on our lives has been one of devastation, destruction and, ultimately, death. The ripple effect from innocent infected victims to the innocent affected victims has seen children, brothers, sisters, aunts,

uncles, cousins, mothers, fathers, husbands, wives, grandparents, in fact, in some cases, a complete generation lost.

But this wasn't only whole blood. Of course, there were blood products. What was the cause of this bloody mess?

Blood products, such as Factor 8 and Factor 9, were also responsible for not only Hepatitis C, but Hepatitis B, HIV and other pathogens, which killed thousands of innocent lives.

Those responsible for this historic and horrific tragedy, which has lasted decades, must be identified. They must be held responsible for the consequences of their actions and prosecuted if necessary.

Just to finish off, I would like to send my sincere thanks to the love of my life, my husband, Dean, who has been my strength and my support, and believed in me and given me the courage to come up and speak out in front of everybody. To my lovely family for being very understanding also. But also to the members of the various groups that I belong to, but especially to those from those Contaminated Whole Blood UK, and also to the Hepatitis C Trust, who have been my friend and ally throughout. Thank you.

SIR BRIAN LANGSTAFF: Thank you, Michelle. Paul Desmond.

Opening statement by PAUL DESMOND

MR DESMOND: Thank you, Brian. Good morning.

First of all, I'd like to start with a question.

I recently read an August 2018 comment from a Department of Health spokesperson that went:

"Hepatitis C infections from blood transfusions were an inadvertent, unavoidable accident for which the terms "liability" and "compensation" are inappropriate."

Does anyone in this hall agree with that statement; that it is an accident; that it couldn't have been done better; that no one made a mistake? Does anyone agree?

Not a single hand. That's what I thought.

So, a quick statement about liabilities or things that went wrong in the Department of Health.

Due to running a medically negligent, filthy blood supply from 1970 to 1991, it seems urgently needed.

Firstly, the planned, avoidable harvesting of hundreds of thousands of units of blood from British prisons was no accident. It was a negligence avoided by many, many nations. It is a joy to see our Inquiry lawyer laptops ablaze with data detailing the mass harvesting of highly infection Hepatitis C prison blood in the UK.

This went on until 1985, at which time Dr Doe harvested some samples and kept them. In 1991, when the

test became available for hep C, he found prison blood was 65 per cent Hepatitis C positive in his samples. This goes a long way, those 500,000 units from prisons, to explaining our peak of 585,000 Hepatitis C patients in 1985. That's the first negligence.

Second negligence. There was a complete failure in the UK to surrogate blood test for liver disease markers blood donations. This was planned and this was no accident. The Gunson Report studied by our transfusion service head executives, in 1985, estimated 40 per cent or 8,000 of our annual 20,000 Hepatitis C transfusion infections could have been avoided with surrogate blood screening.

Third negligence. There was an idiotic notion prevalent in the blood executives, the working party, that Hepatitis C was benign. This idiotic notion was unique to the UK, and it was also created, defended and certainly no accident and it did not happen in other countries.

Fourth negligence. The use of pooled plasma factors, bought, sometimes, from overseas, was chosen over safer alternatives and was also definitely not an accident.

All the above plans were chosen by our blood service and often avoided elsewhere. We were agonisingly slow

in stopping prison blood harvesting, completely out of step at safety testing for liver disease markers, our donations, and even amongst the last in the developed world to initiate ELISA blood testing, in September 1991.

Moving on. I have been asked by the Inquiry legal team to just touch on numbers infected with Hep C via NHS care. This time we truly need to get to the industrial scale of our contaminated healthcare disaster, and get it admitted and get it cared for.

To make it crystal clear, every report from experts in the 1980s, before the cover up, every survey done on testing the transfused, including thousands of blood tests done on the transfused, and every one of the three internationally respected models for counting transfusion Hepatitis in a country, all three models suggest we had approximately 300,000 infected transfusion survivors in England, in 1990. I would very much like to thank our Inquiry team for building an experts statistics group, which will of course drill into this suggestion. Also, for bringing global figures, such as Dr Penny Chan, who are completely independent and more than able to add up these numbers on our behalf in the near future, I hope.

Simply speaking for the lawyers, laymen and press

present, one method to count a nation's contaminated healthcare outbreak is called the per transfusion method. You work out how transfusions a nation did, what percentage were infected, infectious of Hep C, and there you have your number.

In the UK, every report suggests our transfusions were one in 40 infectious, or 2.4 per cent infectious. We did 12 million transfusions from 1965 to 1985, 2.5 per cent of 12 million transfusions gives you approximately 300,000 survivors in 1990.

With this method France noted 400,000 survivors in 1990 infected at a rate of 40,000 a year. In the US, they noted 2 million survivors infected at a rate of 250,000 a year, and this method gives us 300,000 UK survivors, in 1990, infected at a rate of 20,000 a year, and that figure was studied by our blood service in the 1980s.

Sadly, in the UK, we have pretended transfusions were one in 2,000, one in 500 infectious. This wild speculation from spin doctors has created this figure of 28,000 infections. 28,000 is 15 times less than the EU national average or the numbers recorded by Spain, France, Italy, the USA and Poland to name a few.

Another method to understand transfusion infections, it is called the population prevalence method. With

this method you count the number of people with Hepatitis C in your country, you subtract those from injecting drug use and other causes, and that leaves you your contaminated residue.

In the UK there could not have been more than 200,000 injecting drug user infections in 1990, this is according to police reports at the time. At 85,000 infections from other causes. 285,000 from our A5 figure gives us, again, 300,000 NHS healthcare survivors.

The third method is testing of population cohorts. Here, suspiciously, alone in the developed world, the UK has never mass tested its C section or high bleed maternity mothers. It has never tested its child surgery or blood product given children. It has never tested its dialysis, its transplant or comprehensively tested its trauma patients. This hall is full of patients who had to wait 5, 10, 20, even 30 years to stumble upon a diagnosis.

However, some smaller studies have been done, in the UK, of the transfused, and they note, when tested, 1 in 50 transfused children had Hepatitis C. They also note 1 in 14 dialysis patients when tested had Hepatitis C. They also note that heart patients, when tested, were 2 per cent Hep C positive. They also note that

Thalassaemia major patients receiving 100 units of blood were 100 per cent infected.

This level of infection again suggests a far higher level of Hepatitis C infections from the NHS's health care than we have been led to believe.

Finally, on numbers, 28,000 is a figure offered by the only Department of Health in the world to have systematically refused to mass warn and test its patients; it is a figure offered by the only Department of Health in the world that lost two entire tranches of ministerial related notes; it is a figure offered by the only Department of Health in the world to force a settlement out of court on the handful diagnosed in 1990.

None of these are the actions of a health service searching for the truth and infected patients. All of these are the actions of an organisation covering up the facts.

Finally, a brief statement about the UK cover up of the World Health recommended guidelines for testing.

In the 1990s, as France rushed to diagnose 80 per cent of its 400,000 survivors, in the 1990s, as the USA rushed to diagnose its 2 million survivors, our several hundred thousand NHS contaminated healthcare survivors have simply been lied to and denied a safety

test warning; most of them have even been denied the fact that they exist. As the World Health rushed to air its "stop, caution, get tested" message globally and fined the 100 million plus infected via transfusions in healthcare and rushed to warn them that 21 units of alcohol can kill them, that many modern common prescriptions, like paracetamol, can kill them, our health service did next to nothing.

In 1995, in fact, our Chief Medical Officer, Dr Calman, simply stated, instead of half a million people having Hep C, in his letters to GPs and hospitals he said it might just be 50,000, it might be a quarter of a million, "we don't know".

From that point on, hundreds of thousands with contaminated blood from healthcare in their veins were left to die as soon as possible.

It should be remembered that, in France, doctors were imprisoned for the crime of even thinking of leaving people in such danger as ours were left in for decades.

Dr Calman also stated in his letter to the GPs and the hospitals, there are reasons -- wait for this one -- when "it is preferable not to inform patients of their transfusion Hep C infections or risks."

He refused all testing to those infected from 1945

to 1987. In fact, not until the Hepatitis scandal report was tabled in the Commons was any effort made to create a national Hep C testing strategy, in 2004.

Contrast this with the 1990s contaminated blood statement of the US surgeon general, in the early 90s. Dr Everett Koop stated to the American people and the world:

"We stand on the precipice of a grave threat to our public health. It affects people from every walk of life. It affects people in every country and, unless we do something about it soon, it will kill more people than HIV/AIDS."

Our Department of Health spin doctors, when finally bullied into making a plan more than a decade later, decided they needed a small, low key campaign, aimed at not being sensational and focusing on highly marginalised addict groups.

We need to just admit that the UK tripling of cirrhosis and liver cancer in a time of falling alcohol use is motored by our cover up by the fact that 1 in 100 UK citizens had a deadly liver carcinogen called Hep C, at the end of our harvesting blood wholesale from prisons.

This worst in the EU boom in liver death is mirrored by our worst in the EU effort at diagnosing our

contaminated blood survivors.

Sadly, this boom was actually predicted in the Commons in 2002, in the Hepatitis scandal report and by myself, again to Lord Archer, in 2007.

We need to realise, also, that as fast as we have left 300,000 NHS survivors without testing, we have imported up to 200,000 more survivors from contaminated healthcare from overseas with Hepatitis C and Hepatitis B.

We need to understand, if we have lost 20,000 lives to this disaster and its cover up, we cannot afford to lose another similar number.

It doesn't matter if we have an advanced cure for Hep C, it doesn't matter if we have treatments for help B and transplants for both if we don't have the truth to warn people they are infected.

Finally -- I am sorry if this is a little adversarial -- but our health care services harbour a few key Department of Health quangocrats, who have run this cover up, and who see it as their job to protect their organisation and its reputation and perhaps their pensions. We need to claim our health service back from these people and give it to doctors who want to save lives whatever the cost.

We know who these quangocrats are and I hope we will

hunt them down for questioning and, I sincerely hope, punish them after extracting some confessions from them. It may be blood for blood, but it is also justice.

Thank you.

SIR BRIAN LANGSTAFF: Ladies and gentlemen, something like ten minutes early we are breaking for lunch. Can I ask you therefore, please, to be back here by 2 o'clock rather than the 2.05, which is on the programme. I shall see you then.

(12.50 pm)

(A short break)

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