Mr Chairman, I have the 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 - but we also represent clients who are not members of CBC.

The one thing which links all of our clients is that they are, or are related to, individuals who became infected with Hepatitis C and/or HIV as a result of NHS contaminated blood or blood products. Yet despite this unifying feature, our clients have all suffered in different ways and for different reasons; a reflection of the devastatingly large reach of the contaminated blood scandal.

Some of our clients contracted the Hepatitis C virus and continue to carry the virus, and 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, through undergoing one of a number of deeply unpleasant and painful treatments over a period of months, were "cleared" of the virus. However, 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 significant disabilities as a result of carrying the virus or from this initial treatment. Medical treatment may have cleared the virus from their bodies, but they have been left with 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 the Hepatitis C virus, or their relatives – some of whom are deceased - were "co-infected".

However 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 have received warning letters that suggest that 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, 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, in the 1980s, that "mad cow disease" was affecting humans and the climate of fear surrounding beef products. The worry that those who ate infected beef might develop symptoms of this incurable and terrifying disease was widespread but, thankfully, few have shown signs of the condition. 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 by the need, each time one of our clients visits a hospital or a dentist, to explain that there is a risk of transmission.

We welcome the fact that the Inquiry recognises that the "victims" are not limited to those who were infected with viruses as a result of NHS contaminated blood or blood products.

All of our clients live in families and communities and 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, John Dunne, 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 manner of thy friends 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 bell 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 that ex gratia compensation schemes have been set up. But – in the main - they have only offered support to the directly affected victims. My clients ask this Inquiry to be the first occasion on which there is formal recognition of the devastating impact that 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 shaped by the commitment they have to a victim.

We welcome the recognition that this Inquiry offers in its focus on all those whose lives have been affected by these terrible events - only some of whom were infected.

All of our clients welcome the fact that the government has finally agreed to set up this formal Public Inquiry and are determined to do everything they can to assist you, as Chair of the Inquiry, and your staff to undertake the almost impossible job of peeling away the obfuscation, delay and 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.

# 1. The Terms of Reference.

The first thing our clients wish me to address is the width of the Terms of Reference for this Inquiry. Our clients welcome the wide Terms of Reference for the Inquiry and the fact that those terms were agreed following a wide ranging consultation.

You would expect our clients to be rigorous in ensuring that you investigate comprehensively across the whole range of issues raised by your Terms of Reference.

Whilst we understand the need for expedition, we have very clear instructions to ensure

that full respect is given to the width of the Terms of Reference and that no attempt is made to cut them down for either administrative convenience or to spare embarrassment to those administrative decision-makers who are discovered to have been key players in the sequence of events that led to this tragedy.

# 2. How should the Inquiry approach individuals who have been involved in these events but can no longer defend their actions.

Secondly, I must say a few words about the approach we invite the Inquiry to take regarding individuals working for public bodies who made relevant decisions which led to this tragedy — many of whom are no longer able to defend their own reputations because they are deceased, long retired or have no memory of relevant events.

We fully appreciate that there will be an enormous temptation to protect the reputations of those who cannot speak for themselves because they are deceased or, now living in retirement, or cannot recall the details of events that happened so long ago.

Our clients do not want this Inquiry to turn into a "witch hunt". Evidence is highly likely to show reckless, uncaring, incompetent or wholly inappropriate behaviour by NHS or government decision-makers. My clients 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 and 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.

Public officials working for public bodies - whether in the government, within the NHS or elsewhere in the public service - must be held publicly accountable for what they did or did not do. Whilst my clients accept that any judgement must be based upon the information available to a decision-maker at the time, legitimate questions must be asked about what an individual knew, what inquiries he or she made to establish the truth about risks and benefits of a particular course of action, and what he or she ought to have known before

making key decisions. We hope that this Inquiry will not refrain from holding public servants properly to account for their actions or omissions merely because an individual is deceased or cannot now recall the circumstances which led the decision in question. We accept that there will be a fine line to tread between appropriate respect for those who cannot speak for themselves and proper transparency and accountability.

However, 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 could be called to account for the discharge of his or her public functions at an undefined date in the future.

The function that this Inquiry will be undertaking of scrutinising the decision-making of public bodies - carried out by individuals - is one that all public officials know is possible. Public officials are accountable to the public for their actions just as they are paid by the public for their services.

Accordingly, whilst 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 decisions were made by named individuals which led to 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. In the balance of interests between transparency and the protection of reputations, we expect no stone to be left unturned however much overturning that stone reveals events which demonstrate incompetence, a lack of understanding, inadequate inquiry before decisions are made, shortcomings as a result of resource constraints or plain incompetence.

My clients respect the inquisitorial nature of this Inquiry and will not routinely seek to cross-examine witnesses. We may suggest questions to be put by counsel to the Inquiry but accept that choice of questions must be a matter for the Inquiry team to decide. But 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 counsel.

#### 3. Disclosure

Thirdly, I need to say a few words 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. However, these two processes were both utterly inadequate to get to the truth, 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 of 27 March 1989.

But 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 that no action should be taken to reopen inquests or to commence investigations into the possible prosecution of any individual whose decisions may have led to the deaths.

Those who were closely involved with the events knew that the "official" account was far from the whole truth, and yet many also knew that the real story of the events which led to the Hillsborough tragedy had not yet been told.

The families of the 96 also knew the truth had not been told and 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, and inquest and a judicial investigation. But – and this is the chilling lesson we invite this Inquiry to focus upon - 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 out 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 out the truth; official documents were "discovered" for the first time which painted a very different picture to the story that had been told the previous Inquiry and to the Inquests. Eventually, on 12 September 2012 the Hillsborough Panel published its report, properly informed by a vast number of previously undisclosed documents. That led to the new Inquests which, in turn, led to the findings handed down by the jury on 26 April 2016 that the 96 Liverpool fans were unlawfully killed.

My clients are entitled to believe that there are lessons that this Inquiry can learn from that process.

Very considerable credit needs to be given to the late Lord Archer of Sandwell, the former Solicitor General, who chaired a non-statutory inquiry into the infected blood scandal, which reported in 2009. However 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, in order to draw a line under this disaster"

We understand that there are reports that the private papers of the former Secretary of State, Dr David Owen, were part of this destruction exercise. That is clearly something that 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 government of the day.

If it is true that civil servants deliberately destroyed documents to "draw a line" under the disaster, civil servants were the only individuals who could walk away from this disaster as a result of this deliberate act of wanton destruction of public records. My clients were required to live with the consequences of the decisions of public officials for the rest of their lives, and many had their lives cut short as a result of those decisions.

But the reality is that a single copy of any document is a rarity in government. The nature of government is that multiple copies of any significant document are created and are filed in numerous different places. Not every civil servant will have considered that the deliberate destruction of documents was an appropriate policy response to this disaster. My clients are confident that it is possible to find copies of virtually all documents generated by government in relation to this disaster, albeit that it will be a massive task, will require persistence and ingenuity and will require the Inquiry's investigators to use all the skills and techniques demonstrated in the Hillsborough and Gosport inquiries to uncover the full story.

We also welcome the clear statement by Jenni Richards QC yesterday that the Inquiry has an expectation that bodies responding to its requests for disclosure will give careful consideration to waiving legal professional privilege. Legal professional privilege cannot be used as a shield to prevent those who were paid by the public from being accountable to this Inquiry. We hope the government will accept that, whatever the embarrassment or potential financial cost, the time for secrecy about what really went on is over. Just as legal professional privilege can be overridden in the public interest under the Freedom of Information Act 2000, legal professional privilege should never be raised to prevent the full truth being disclosed to this Inquiry.

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

However, part of the role that we envisage playing on behalf of our clients is to ensure that the Inquiry team and the relevant public bodies assist the disclosure exercise to the best of their abilities, however awkward or embarrassing disclosures may be.

## 4. Warnings.

The Terms of Reference rightly focus on the sequence of events that led to this disaster and to the information that was provided to the government that ought to have led to an

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 or should have been given and how both the government and the NHS delayed before acting on the warnings. It is clear that the failure to act earlier resulted in deaths and blighted lives.

We will support the Inquiry in rigorously investigating how infected blood and infected blood products came to be used by the NHS for such a long period and inflicted such devastating consequences on those who were unfortunate enough to be victims of this tragedy.

#### 5. Informed Consent.

The issue of informed patient consent lies at the heart of the delivery of any lawful medical treatment. Following the seminal judgement in *Montgomery*, informed consent has been established to be part of the common law. However, the case clarified that the common law imposed a requirement for informed consent, but it did not change the law. The need for any medical consent by patient to be informed has always been present, even if it did not have proper focus prior to a sequence of cases leading up to *Montgomery*.

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 different nature of the risks faced by those with severe, moderate or mild bleeding disorders. The Inquiry will 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 that they were running, particularly where there was no immediate urgent need for the application of blood or 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 patients had the risks of such prophylactic treatment explained to them - or not explained to them - is plainly a relevant area for this Inquiry.

## 6. The source of the infected blood or blood products.

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

## 7. Disclosure to infected patients.

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

## 8. The attempt to deflect the blame away from the NHS.

The Inquiry will also want to know why so many infected patients were accused of having acquired the virus by drug taking, alcoholism, sexual promiscuity or any number of other potential reasons. The experience of victims is that the NHS was often keen to attempt to find any cause as to why an individual carried the Hepatitis C virus other than admitting that 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 existence of supporting evidence in any individual case. The damage caused by blaming the victims cannot be underestimated.

#### 9. 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 NHS decision-making have never been prioritised for emerging curative or symptom alleviating treatments by the NHS. The argument has always been advanced that the NHS cannot prioritise the treatment of some individuals who carry a virus over others who carry the same virus, based upon the underlying cause of their infection. This Inquiry will have to look to determine whether that is a morally defensible position or appropriate way for the NHS to respond. This raises profound questions but, in summary, the position of my clients is that they are entirely blameless for the disabilities inflicted upon them by the NHS and therefore they ought to be at the front of the queue for any emerging treatments.

#### 10. Medical records.

There is enormous concern amongst my clients about a pattern of the NHS repeatedly 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 relevant records from these particular patients was unrelated to the cause of their infections. Was this a case of the NHS getting rid of the evidence of past sins? If so, who organised it and who made the decisions?

The Inquiry will want to look to see the extent to which this is supported in the evidence and why 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 to attempt to limit the reputational damage to the health service?

# 11. The role undertaken by other parties.

Whilst the main focus of this Inquiry will undoubtedly be on individuals working for the government, ministers and senior officials in the NHS, there are a large number of other bodies whose actions or omissions played a significant part in this sequence of events or

influenced disproportionate, unbalanced or inappropriate responses to the tragedy. The prioritisation of one group of victims over another may appear entirely justifiable to somebody promoting the cause of those victims but it is easy to see that, objectively, different victims groups have been treated in different - and indefensible – ways throughout the sorry history of this tragedy.

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

# 12. Mortality rates.

That differential approach is perhaps best illustrated 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 that 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 need to conduct a detailed analysis of the data held by the five previously separate ex-gratia schemes. This information will need to be collated in such a way as to show how the mortality rates of the infected community have changed over time. There are five specific categories that we would urge the Inquiry to focus upon in this undertaking:

- a) Co-infected patients at HCV stage II;
- b) Co-infected patients at HCV stage I;
- c) Mono infected HCV patients at stage II;
- d) Mono infected HCV patients at stage I; and
- e) Mono- HIV patients.

#### 13. Support for the spouses, partners and children of victims.

It is mystifying as to how anyone in government might have thought that 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 or blood products but to deny a similar level of financial support to spouses, partners or children of individuals who died as a direct result of acquiring a different type of virus from NHS infected blood or blood products. However, until very recently, that was how public money was used across the various schemes set up by the government.

This Inquiry will want to look to see how that indefensible set of circumstances emerged and why no steps were taken to correct this obvious disparity.

## 14. 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 its investigations in order to produce a report too quickly, but equally we commend the steps that have been taken to proceed with the Inquiry as expeditiously as possible.

Can we invite the Inquiry to focus now on the steps that will be taken following the end of the evidence. My clients are particularly concerned that this Inquiry should learn the lessons from other Public Inquiries where there have been very extensive delays- sometimes running two years between the conclusion of the evidence and the publication of a final report. Some delay is entirely inevitable and proper. However, other recent Public Inquiries have been dogged by endless disputes - often litigated in the courts - 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. 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 all other participants who are excluded from the debate about the extent to which any individual or organisation is being criticised.

Individuals who give evidence in a court of law do not have the opportunity to debate the merit of the Judge's conclusions before publication of the 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 to produce this report as quickly as possible, 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 that this may, on occasion, mean the Inquiry recalling individuals to give further evidence or giving organisations the opportunity to answer criticisms which emerge at a later stage of the evidence. But such a process has three distinct advantages.

First, it is fair and gives due respect to the human rights of all participants. The confidential debate and any 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 considerably 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 the Inquiry has rightly committed itself.

We invite the Chair to reflect on whether this is an area where he considers it appropriate to set out the ground rules at the outset of the Inquiry.

## **Summary**

Our clients have lived with this blight over their lives for decades. They have repeatedly knocked at the door of government to ask for answers, knowing that every year that passed would make the task of finding answers more difficult. This will be their final chance of securing truth and justice for those still living, albeit they are suffering profound disabilities as a result of this tragedy. The Inquiry is also an opportunity to recognise the extent to which lives were cut short for those victims who cannot take part.

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

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 does not guarantee that future decision-makers will not follow a similar course in the future. But the legacy of a report which understands how things went so terribly wrong is that the chance of another tragedy can be greatly reduced.

Our clients will therefore endeavour to see this Inquiry process as a co-operative venture between everyone concerned, with the focus on establishing a comprehensive account of who, how, why and when decisions were made that blighted the lives of thousands and led to so many premature deaths.