**THE INFECTED BLOOD INQUIRY**

**Opening statement for the infected and affected core participant clients represented by Thompsons Scotland**

**25 September 2018**

## 1. INTRODUCTION

1.1 I am Aidan O'Neill QC, and I appear - along with my learned friends, Mr Jamie Dawson and Ms Kirsten Sjøvoll - on behalf of almost 250 core participant infected and affected clients who are represented before the Inquiry by Thompsons Solicitors, Scotland.

1.2 On behalf of those whom we represent we thank the Chair for affording us the opportunity to make this opening statement on behalf of them.

1.3 The very fact that we have been given the opportunity to make the Opening Statement distinguishes the Infected Blood Inquiry from what occurred in the *Penrose* inquiry. We hope and trust this is not a form of gesture politics and that the important points we make on behalf of those whom we represent will be listened to and taken on board

1.4 Those whom we represent include the charities Haemophilia Scotland and the Scottish Infected Blood Forum. These charities have worked and campaigned for many years in seeking to represent the interests, and ensure respect and protection of the basic rights [1] of *all* those who have been infected and affected in Scotland by the contaminated blood disaster.

1.5 The circumstances in which the individual core participants whom we represent came to be infected with, or affected by, to all blood borne pathogens,- notably Hepatitis B and the Hepatitis C virus, HIV and vCJD - are such that there are reasonable grounds for taking the view that the injury - and in many cases deaths - which they have suffered resulted from *wrongful* acts on the part of those responsible for providing supplies of blood for the

[1] The setting up of the inquiry undoubtedly falls within the ambit of the Thompsons core participants' Convention rights, in particular their rights consequent upon the procedural obligations imposed on public authorities by virtue of Article 2 ECHR and Article 3 ECHR: see *Kennedy and Black v Lord Advocate* [2008] CSOH 21, 2018 SLT 195 per Lord Mackay of Drumadoon at § 75.

blood transfusions which they, or their relatives, received and/or the blood products with which they, or their relatives, were treated.

1.6 This inquiry is, for us, an exercise:

- in establishing the truth of what happened;
- in bringing past and on-going wrongs to light;
- to learn the lessons from the disaster to protect all patients who reply on the NHS for safe treatment
- in calling those responsible for past failing to account; and
- in providing the opportunity for those who were responsible:
  (i) to acknowledge and accept responsibility for the wrongs that were done by them and on their watch, and
  (ii) to apologise fully and unequivocally for the harms they caused.

1.7 We have spent the last couple of weeks in the run up to this preliminary hearing of the Inquiry meeting with many of the 250 individuals and organisations across Scotland whom we have been asked to act for before this Inquiry.

1.8 In accordance with *their* wishes and instructions, I would like to use this opening statement to address the Inquiry on the following matters:

1. The clients and their experiences;
2. The purpose of this public inquiry;
3. The terms of reference;
4. Procedural experiences and expectations;
5. The future; and
6. Conclusion

## 2. THE CLIENTS AND THEIR EXPERIENCES

2.1 You, Sir, have, been keen to stress in the documentation which the Inquiry has promulgated in these, its early stages, that you are determined to put at its heart the *people* who have been infected and affected by the contaminated blood disaster. You have said that it is *their* experiences which must shape the whole Inquiry.

2.2 This is entirely right and proper.

2.3 I would like to take the opportunity of this opening statement first to tell you something about those people, the people whom I represent, the people whom you say you intend to put at the centre of this process.

2.4 It is only by hearing and heeding the stories of these people that you will, Sir, be able properly to direct and conduct this Inquiry.

2.5 In my meetings with those I have been asked to represent before you, I have been humbled in listening to their accounts of how their own lives have been blighted and burdened by infection. I have heard their righteous anger. I have learned of their burning desire to uncover the truth and for justice to be done.

2.6 These individuals come from all walks of life, all social classes, all backgrounds, all age groups. Their stories are different in their details. However, they are united by many common themes. These people share the background that they sought medical care when they needed it the most. They include, among others:

- adults and children with inherited genetic bleeding disorders;
- people who were given blood transfusions after being injured, often in car crashes; sometimes in industrial accidents;
- mothers who were given blood after giving birth.

2.7 *All* of our clients put themselves in the hands of the National Health Service when they needed its help and were at their most vulnerable. They trusted the doctors to whom they turned. They trusted their medical expertise. They trusted that the medical staff would help them and give them the best care that they could. They presumed that their doctors would have available and would only use *safe* products to alleviate their conditions and treat their injuries and that they would be nursed back to health. They trusted the Government to ensure the safety of blood and blood products used by the NHS.

2.8 Instead of this, so often they and their families, friends and loved ones left the hospitals where they had been treated *not* healthier, *not* cured; but instead crucially weakened, their health fundamentally, permanently and irretrievably compromised.

2.9 They have been left with life threatening diseases, in many cases which were far worse than the original conditions for which they had sought medical assistance

2.10 Many of those infected have subsequently been subjected to painful and debilitating experimental and untried therapies which have left them sometimes permanently weakened; further compromising their health, yet without successfully clearing them of the viruses with which they have been infected or curing the conditions to which those viruses have given rise.

2.11 They have been left with their faith in the system of medical care shattered as a result of secrecy and evasiveness about their conditions and the circumstances their infections.

2.12 Whether as a result of losing loved ones or as a result of their infections, many feel that the lives they had, have been *stolen* from them. Their exposure to contaminated blood has led in some cases to early deaths. In other cases there have been decades, since infection in childhood or early adulthood, of ill health and a multiplicity of conditions to be treated, often with painful and debilitating early experimental treatments.

2.13 For many of the infected and affected lives have been lived fearfully – dogged by depression about their present lives, and anxiety about the future. They have lived, and in many cases died, in the *shadow* of infection. The lives that were left to them by the contamination were not the lives they were *supposed to lead*.

2.14 What they tell us they want, however, is Answers. Why did this happen? What could have been done to stop it happening? How can we ensure that nothing like it ever happens again?

2.15 They wish the reasons for their lives being stolen from them to be uncovered. They wish the extent of what they have lost to be understood and acknowledged by the state and the individuals who stole it from them.

2.16 Amongst our clients are the parents of children with bleeding disorders who died as a result of contracting hepatitis C and HIV at Yorkhill Children's hospital after receiving blood products which came from paid donors in the United States. Our clients include mothers who, having genetically passed bleeding disorders to their sons, desperately sought the best care for their sons' conditions, to make and keep them safe. At Yorkhill these children with haemophilia were exposed to aggressive new treatments and therapies. Under the new regime of using clotting agents as a prophylactic to prevent uncontrolled bleeds rather than reactively to bleeds once they had happened, the immediate responsibility for the injection of blood products such as Factor VIII was passed on to the

parents to carry out at home. They took on this task gladly. And then it turned out that the very injections which they were told to give their sons were the very cause of their subsequent infections and diseases, so much worse than their original condition, which led in so many cases to the premature deaths of their sons, and their parents' life-long suffering.

2.17 We are encouraged to hear that the Inquiry intends to look at the effects on those "affected" as well as those "infected". The fact that inherited bleeding disorders tended to affect multiple members of the same family means that this disaster destroyed entire families, with multiple members being infected.

2.18 Our clients also include individuals who developed conditions and diseases as a result of receiving contaminated blood or blood products which their treating physicians knew little, if anything, of.

2.19 In some cases when they sought treatment, our clients were stigmatised by healthcare professionals, blamed for their conditions, accused of being drug addicts or abusers of alcohol. Their medical records during their lives and sometimes their death certificates baselessly recorded and maintained these false accusations, based on ill-founded assumptions and prejudice and ignorance. They asserted that the patients were themselves to blame. Such records did not acknowledge that the State had caused these conditions by its own reckless and abusive conduct.

2.20 Those who lived have in many cases had to endure horrific treatment regimes, sometimes alone and often with little or any aftercare. In some cases these treatment regimes were simply *intolerable*; they gave rise to mental and physical consequences which were experienced as *worse than* the original infection.

2.21 There are frequent tales of enduring, unrecognised mental health problems, despair and desperation driving some to suicide. Of children being forced to share wards with adults and watching them die in front of their eyes. Of spouses watching their partners changing overnight from loving partners and parents, from functioning members of society to shells of their former selves. This disaster ruined lives and ruined families.

2.22 The fact of infection and its medical and social consequences for the infected and affected requires to be fully explored and understood. At times, the stories which one hears are hard to believe. It is the duty of the Inquiry to listen to them.

2.23 The individuals and organisations whom we represent are *not* bystanders. They have rightly all been recognised as core **participants**. They are ready and willing to participate in this process. They expect to be able to do so. Many were involved in the Penrose Inquiry. Many were denied core participant status in that inquiry. The Penrose Inquiry failed to give more than a handful of infected and affected people the chance to be heard by giving evidence before it. *Penrose* instead relied heavily on the evidence of doctors, such that it appeared to be "captured" by the medical establishment and biased against the voice of the patients and their families. In many cases for those whom I represent, the experience of *Penrose* only added to their sense of frustration, rejection and loss.

2.24 As one would expect in such circumstances, the infected and affected turned to the medical and governmental agencies, which were charged with their care. They expected support. They expected answers. They expected to be treated with respect. Instead, what they found was secrecy and cover up.

2.25 It is your responsibility, Sir, to investigate and expose the extent of that cover up. The response from these agencies has bred mistrust. It has undermined and destroyed previously functional relationships between families and medical professionals upon who they relied for their care. The lack of recognition in the early stages that they had been infected and the lack of willingness to be honest about why has led many of the infected and affected whom we represent to seek their own answers. The secrecy has bred mistrust which has bred contempt which has bred theories of conspiracy. People have looked to other parts of the world where similar situations have given rise to criminal prosecutions. People have looked to other places like Ireland where victims have been better treated than they have in this country. This has quite justifiably led to people wondering if they were victims of criminality and that is why the response has been to cover up what went on.

2.26 That this was allowed to happen in a civilised nation such as our country aspires to be is a national scandal which our society must take every step to prevent happening again. These things ought not to have happened by any standard. People ought to have been protected, involved and given a choice. You will hear that they were not.

## 3. THE AIMS OF THIS PUBLIC INQUIRY

3.1 The Inquiry has been set up and its terms of reference have been fixed.

3.2 The Inquiries Act 2005 within which it will be conducted affords room for interpretation of what the Inquiry is meant to achieve, what kind of Inquiry it seeks to be. Useful Guidance can be obtained from a recent House of Commons Briefing Paper entitled *Statutory commissions of Inquiry: the Inquiries Act 2005* (30 January 2018, number SN06410). This suggests that a public inquiry such as this may serve a number of purposes. We think that these objectives merit some careful consideration as we start this inquiry.

**Establishing the facts**

3.3 The first objective of an inquiry is **establishing the facts.**

3.4 We expect the Inquiry to ensure that the relevant facts are fully, fairly and fearlessly investigated and exposed to public scrutiny. If not, there is a danger that the Inquiry will not only fundamentally disappoint but will also fail comply with the Convention rights of the infected and affected implicit in the procedural obligation of articles 2 and 3 ECHR.

3.5 What happened in a number of areas, in particular the area of scientific developments nationally and internationally, is documented relatively fully within the Penrose Inquiry materials. But we will expect the Inquiry to do additional work to establish the facts in relation to pathogens, other than Hep C and HIV, and on the issue of cover-up in particular.

3.6 And there remain after *Penrose* factual disputes in areas where the voices of the clients were not heard, such as the way in which information was passed to them about risks in the products to which they were exposed, about testing which was conducted on them and about the fact of their infections and about contemporary knowledge about what being infected meant.

3.7 We will in due course come to specific observations about the way in which the Penrose Inquiry was conducted, but we think that some preliminary observations would be appropriate at this point.

**The Penrose Inquiry and the Penrose Report**

3.8 The Penrose Inquiry started in 2008 and ran until 2015. It had access to over 100,000 documents. Its terms of reference were more restrictive than the remit of this Inquiry, which we will touch upon in more detail in moment.

3.9 Following a successful judicial review which quashed the decision of the Lord Advocate to deny a statutory inquiry into a number of deaths of individuals who had been infected by contaminated blood, [2] the Penrose Inquiry was set up by the Scottish Government. The UK Government was not involved in this process. We don't know why. The opportunity was however lost then to hold a UK Inquiry. This would have been more cost effective, and would have avoided years of additional delay. As it is *Penrose* was a Scotland only inquiry and was concerned with primarily just medical issues relating to infections which occurred in Scotland by blood contaminated with hepatitis C virus (HCV) and HIV.

3.10 The Penrose final report was published in 5 volumes. The report runs to 1,780 pages. The executive summary runs to 44 pages. The initial part of the Inquiry involved the ingathering of material which led to the publication of a preliminary report (running to 614 pages) which was meant to set out a framework of relatively uncontentious matters which could form the basis of the further work of the Penrose Inquiry, namely the oral hearings and the compilation of the final report.

3.11 The only input from the infected and affected into the compilation of that preliminary volume was into chapter 4 which contained some narrative of patient and family experiences. Otherwise, that was compiled by consultation with other agencies including the NHS. It was compiled behind closed doors. It was assumed to contain an uncontroversial narrative without allowing any patient participation in its creation. Patients were excluded from finding the answers to questions which mattered to them a great deal.

3.12 Despite these shortcomings, the Penrose Report stands as a useful and detailed account, split into sections with topic headings, of factual material relating to the events of the contaminated blood disaster. It contains a good deal of scientific information which, in our view, would not require to be looked into again or examined in the same detail. For example, the information from the UK Haemophilia Centre Doctors Organisation about the amount and types products produced and used in Scotland over the reference period shows the patterns of product use (on a population level and for individual patients) and could form the basis of a proper analysis of why these patterns came to exist.

3.13 The Penrose Report also contains a useful analysis of some uncontentious scientific concepts and processes which need not be set out again. The Penrose Inquiry did a

[2] *Kennedy and Black v Lord Advocate* [2008] CSOH 21, 2018 SLT 195

considerable amount of work on this Inquiry's term of reference 2 to uncover the numbers infected, in particular in relation to epidemiological analysis of the number of transfusion related hepatitis C infections – this need not be repeated thought the conclusions may be subjected to some further analysis.

3.14 The chapters on heat treatment of products in Scotland (in themselves running to 106 pages in the preliminary report and 141 pages in the final report based on many, many hours of oral evidence) stand as a useful narrative of this scientific aspect of the matter, in Scotland at least. The Report contains a useful chronology of correspondence as to what was said by whom, to whom and when. It should be noted that although focussed on Scotland that chronology extends beyond Scotland to other parts of the world.

3.15 Where the Penrose Inquiry failed, in our view, was in its failure to analyse the facts, to ask why things happened, to go beyond anything more than a factual account. It failed to recognise the other significant purposes of a public inquiry and failed to make recommendations which it could and should have made. This Inquiry needs to go beyond the establishment of what happened and establish clearly *why* the infections happened. It needs to realise that a public inquiry is *more than* an accounting and fact-finding exercise.

3.16 Further, the Penrose Inquiry failed at any time to define and apply an appropriate standard by which the actions of those responsible could be *judged*. The approach was as if the Penrose Inquiry was clinical negligence litigation. Prevailing medical opinion, often defined in evidence by the very doctors whose treatment caused the infections, however misguided by modern standards, was deemed to be a complete answer to any question. Absence of evidence of any contemporary criticism for any given practice meant that no criticism of that practice could be made by that Inquiry.

3.17 *This* Inquiry needs to ensure that it hears from truly independent medical experts and medical ethics experts, both in assessing what was done by the standards of the time, *and* by the standards of the present.

3.18 We note the intention to appoint Expert Panels and the invitation for input by Core Participants. We trust that this will extend to Core Participants being able to make such representations as may be appropriate about the appointment of experts already appointed by the Inquiry.

3.19 Moreover, important events and decisions were ultimately determined to be merely "*unfortunate*" by the Penrose Inquiry final report. That choice of language is not helpful

as it seeks to avoid taking a view about responsibility. In several places the conclusion was reached that there was "*no evidence*" of failings. This was due to defects in investigation in certain instances, in our view.

3.20 The Penrose Inquiry in places merely *noted* certain matters, for example the fact that donors with a history of blood transfusion or haemophilia were excluded from donor sessions in May 1983 – as a result of the risk they may be virally infected – which was in contrast to the advice about risks being given to such patients at the time (page 27 of the Executive Summary). No analysis. No attribution of responsibility. Merely noted.

3.21 In contrast to proactive donor exclusion in the east of Scotland in the early 1980s, the west of Scotland's lethargy in excluding high risk donors is described as a "less constructive approach". A passing comment. No analysis. No attribution of responsibility.

3.22 The possibility of the cessation of concentrate use for bleeding disorder patients in response to the emergence of the threat of HIV was described as a "*minority view, rejected by a large body of informed opinion*" (page 18 of the Executive Summary). This is an observation of fact, not an analysis of the appropriateness of that opinion in light of the risks.

3.23 The Penrose Inquiry concluded that it was reasonable to continue to use these products at that time "provided they were used on a more discriminating basis" (ibid). As it was not found that they were, their use was in fact unreasonable, we assume, though this was not said.

3.24 Use of information about patients for studies of immune function without their knowledge was described in the words "*aspects…could have been handled better*". It was observed that there was no fixed ethical rule which this offended and so no rule was broken (page 37 of the Executive Summary). No analysis. No consideration of the patients.

3.25 Of course, the Penrose Inquiry also refused to look at many important areas and to answer many questions of significance, which we will come to in due course. These observations are examples of the flaws in the overall approach which, in our view, led to the conclusions of the Penrose Inquiry being unsatisfactory. What was reasonable in the interests of the patients whose wellbeing the production and use of blood and blood products were designed to serve is what *this* Inquiry should consider.

**Accountability, blame, and retribution**

3.26 As the House of Commons Briefing paper identifies, the second purpose of a public Inquiry like this is to achieve **accountability, blame, and retribution**.

3.27 Paragraph 10 of the terms of reference refers to the identification of *individuals* who might be said to have been responsible for or to have caused or contributed to the contaminated blood disaster.

3.28 Those whom we represent are aware that both individuals and organisations are responsible for what has happened to them. They wish justice for themselves and for their loved ones. They wish those individuals and organisations to be held accountable.

3.29 They also wish it to be understood that the reaction of the state to their infections has merely exacerbated and contributed to the way that they feel. This must be understood and those responsible at the time and subsequently must be held accountable.

**Catharsis**

3.30 The third objective from the Briefing paper to which we would like to draw your attention, Sir, is the goal of **catharsis**.

3.31 The Inquiry must provide an opportunity for truth and justice – and perhaps, in time, for reconciliation and resolution - by bringing protagonists face to face with each other's perspectives and problems.

3.32 It is important to understand that our clients are people who were let down by the system. They were let down by doctors, by the blood transfusion services, by government both at the time of their infections and in the years when they sought much needed help and answers. They have been patronised and spoken down to.

3.33 It is a fundamental purpose of the inquiry, as far as we are concerned, for our clients now to be heard and heeded. The consequences of the contaminated blood disaster are part of a story which requires to be listened to. This Inquiry needs to provide a space for individuals' stories to be told. It is a requirement of justice- and is confirmed by the case law of the European Court of Human Rights - that the voices of the infected and affected be heard and listened too: cf *D v Commissioner of Police of the Metropolis* [2018] UKSC 11 [2018] 2 WLR 895.

**Learning from events**

3.34 A fourth aim of this inquiry must be learning from the past and so helping to prevent what happened from happening in the future by synthesising or distilling lessons which can be used to change practice. So, this inquiry must provide an informed and independent assessment of *why* these things were allowed to happen, *why* these peoples' lives were ruined as they were.

3.35 You and your team require, in our view, to apply an independent assessment to the facts which are uncovered. You require to challenge those who were responsible within the medical community, the commercial world and the government and hold those responsible accountable for what they did, or culpably failed to do.

3.36 The extent of the system's failure needs to be uncovered and deemed unacceptable by any reasonable standard. The reasons for the failures need to be exposed.

3.37 Those whom we represent are *entitled* to know why this happened to them and to press this Inquiry to ensure that it, or anything akin to it, never happens again. They want to know what *ought* to have happened. Doctors and other professionals cannot be allowed to excuse their actions or to hide behind the support of colleagues on the claimed basis that they were just acting in accordance with the accepted professional practice of the time and thereby put them beyond contemporary criticism. That in many ways was the besetting error in *Penrose*.

3.38 Learning from events *does* mean applying the judgements and standards of today to what happened in the past. Only by recognising that what was done in the past was and is *unacceptable*, will we learn how properly to treat others now and in the future.

3.39 We hope that the Inquiry will help to prevent their recurrence of the failings identified by recommending changes in practice, in particular in the ways in which the medical profession interacts with its patients in the post-*Montgomery* world.

3.40 An Inquiry like this stands every opportunity to being able to find the answers, redress the balance and provide comfort and hope for the future. In order to do so it must not be part of the paternalistic, uncaring system which these people have experienced for so long. It must, in order for them to be engaged with it and to provide an opportunity for it to be

successful, not look at them in the same way. We have every hope and confidence that it will not do so and that the Inquiry will be a success.

**Rebuilding public confidence**

3.41 The remaining objective of the Inquiry identified by the paper which we consider to be relevant is that of rebuilding pubic confidence by showing that the government is making sure all relevant matters are fully and properly and openly investigated.

3.42 The Inquiry needs to aim to reassure the public that lessons can, have been and will be learned, not by paying lip service to the issues and refusing to make recommendations but by understanding in 2018 that this will not be allowed to happen again, to these patient communities or to any others.

3.43 We trust that the Inquiry considers *all* cases of infection to be important. We understand that all cases cannot be looked at. However, we would advise against thinking that because there is only a few, or even only, *one* infection which can be identified as having occurred in a particular time or place this is irrelevant to the Inquiry or that from even a single story lessons cannot be learned about attitudes and practice at that time which can have wider implications for understanding and fulfilling the Inquiry's remit.

**The need for Scottish Government core participation in this Inquiry**

3.44 For those whom we represent, then, the Penrose Inquiry represents a lost opportunity and is unfinished business. We therefore share the concerns expressed by Counsel to the Inquiry at the failure to date of the Scottish Government to apply to come into this Inquiry as a core participant. That failure has not been well received by those whom we represent. Damning words such as "cowardice", as showing an "appalling attitude", a "shocking misjudgement" and an "embarrassing" failure on the part of the Scottish Government – particularly against the fact that so many Scots - survivors of *Penrose* you might say - have been recognised as core participants in this Inquiry. We don't understand why the Scottish Government has apparently changed its position from when Shona Robison, the then Scottish Secretary of Health, wrote to the Prime Minister on 27 October 2017 confirming that she "expected" that the Scottish Government along with the other administrations in the UK - would each be represented as core participants to the inquiry with legal representation.

3.45 Those whom we represent, believe that notwithstanding that it set up the Penrose Inquiry and instructed Counsel to maintain, in effect, a watching brief at it, there are many lessons which the Scottish Government may yet learn from *this* Inquiry. That the position of the Scottish Government appears to be that it wishes to rest with the conclusions of *Penrose* is, in our view, wholly unsatisfactory (though much stronger words than that were used than that by our clients)

3.46 We consider that the Scottish Government needs to be here - to hear evidence not just of the circumstances of individuals' initial infections, but of how those individuals and their families have been treated thereafter. The contaminated blood disaster is *not* something which happened in the past, before devolution. It cannot be dismissed as something of little concern to the present Scottish Government under our current constitutional arrangements. The contaminated blood disaster continues to be lived and experienced in Scotland in the present by the survivors. Issues around how the infected and affected in Scotland have been treated in the 20 years since the devolved Scottish Government was established will be raised before the Inquiry.

3.47 We also consider that the Scottish Government needs to be here to help the Inquiry come to its final recommendations. We will be asking, on behalf of our clients that the Inquiry recommend a range of measures in relation to those infected and affected by the contaminated blood disaster. Given that the vast bulk of our clients live in Scotland, many of the recommendations we seek will directly impact upon the Scottish Government. The measures we will be pressing the Inquiry for may include:

- making available a package of financial assistance which *fully* recompenses individuals and families for the losses they have suffered due to the contamination, and which provides for their on-going and future needs attributable to the contamination;

- 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 ; and

- the provision of dedicated on-going support services for the promotion of the emotional and social well-being and the protection of the mental health of the survivors.

3.48 For all these reasons we, on behalf of our clients, are happy to lend our support to the call made by Counsel to the Inquiry for the Scottish Government to become a core participant. We do not expect that this means that they will have to have Counsel here for every hearing, any more than we intend to have our full team of counsel sitting in on every hearing. That would mean, however, that the Scottish Government is fully part of the process of the Inquiry. We consider that having the Scottish Government as one of the core participants will assist the Inquiry to fulfilling its terms of reference in their entirety, and that is all to the good. So we formally call on the Scottish Government to reconsider its attitude to this Inquiry and recognise its worth and its importance to so many us across these islands, and come and joint it as a core participant.

## 4. THE TERMS OF REFERENCE OF THIS INQUIRY

4.1 The Inquiry has invited us to consider the terms of reference and to highlight any areas which we think should be prioritised.

4.2 In essence, we recognise that the terms of reference are wide enough to permit a thorough examination of the contaminated blood disaster and its consequences. It would be wrong of us to seek to diminish any of the important areas which the Inquiry has recognised as meriting inclusion in its terms of reference. However, we do have the following observations at this stage on particular matters of concern to our clients where the general process needs to focus its attention.

4.3 It should be borne in mind that from the perspective of those whom we represent, although they were initially given the hope of a public inquiry by the Scottish Government the resulting Penrose Inquiry simply turned its face against looking at many areas which the clients rightly considered to be important.

4.4 Among other things, the Penrose Inquiry did not consider *at all*:

- the issues of cover-up, both at the time of the infections and subsequently (term of reference 9 here);

- the reasons why medical records or other documents have been lost or destroyed (term of reference 9(a) here);

- the risks from viruses other than HIV or hepatitis C (term of reference 3 here); or

- the financial consequences (term of reference 4(a) here) and systems of financial support for the infected or affected (term of reference 7 here).

4.5 Since none of these matters were looked at, at all in Penrose, it is hardly surprising that these are amongst the things which our clients wish *this* Inquiry to look at in particular depth. We are encouraged to see that these matters *are* to be fully examined in this Inquiry.

4.6 We also to take this opportunity to stress the importance of the need for further research around the issues of the effects of multiple and continued exposure to blood borne viruses and the of person to person infection, which have been relatively neglected as research topics but which has been of concern to those whom we represent throughout their lives following infection..

4.7 It should *not* be assumed, however, that because other areas *were* included in the terms reference that the Penrose Inquiry did have, then those were considered by it fully, openly or fairly. Those whom we represent do not consider that they were. The sense of injustice and isolation which those whom we represent had come to feel was only exacerbated by the way they were treated within the Penrose Inquiry. So while the Penrose Report might usefully be mined for certain bare facts and the chronology for certain events which it establishes, it cannot be relied upon for the conclusions it reached.

**Cover up**

4.8 One particular area which was expressly not looked at in *Penrose* was the question of cover-up (term of reference 9 here). The position which was taken in that regard in *Penrose* was consistently to the effect that there was no basis for a suggestion of a cover-up and so it did not merit being looked at.

4.9 It is of course inherent in the nature of concealment that those from whose eyes matters are concealed, do not *know* what has gone on. It is important to understand that this, Sir, is an inquiry. Those whom we represent have, in certain areas, developed an expert understanding of and have reached conclusions about what they think has happened to them. But there are areas where they cannot know what has gone on. That is why we are here. To find out what did.

4.10 Having said that, questions in this area have focused on things such as

- the use of Crown Immunity to prevent investigation of domestic manufacturing processes,
- restrictions on press investigation and reporting of the disaster,
- evidence of destruction of medical and governmental records and
- the failure to heed legitimate calls for independent inquiry.

4.11 This Inquiry must resist the temptation to be restrictive in its understanding of its terms of reference. Particularly on the issue of cover-up it must seek to uncover what has been hidden and officially denied and it must go where the evidence leads.

4.12 In due course, we intend to address the issue of the way in which the Inquiry might most effectively be structured. However, before doing so, we have certain notes of caution about the way in which the structure of this investigation may impact on the likelihood of it successfully fulfilling its terms of reference.

**The danger of being mired in, and blinded by, science**

4.13 HIV and hepatitis C do not exist in isolation, though they give rise to different scientific questions and considerations. This observation manifests itself most obviously in patients who have been co-infected but also does so in slightly more subtle ways. To talk, for example, about what was known of the risks of contracting Non-A/Non-B hepatitis or HTLV-3 in isolation would be misguided.

4.14 The emergence of knowledge about the risks and consequences of contracting these viruses happened in real time, to real patients and in a context where the risk of viral infection from blood and blood products in some form had long been known.

4.15 We consider it important to realise that in separating out considerations of why individuals became infected with HIV on the one hand and hepatitis C on the other, one runs the risk of becoming overly concerned with the science associated with those particular viruses.

4.16 It must be remembered that these disasters befell real people. Even scientific topics have as their end point the ruination of individual lives. The separation between “scientific” and “patient” topics is therefore an artificial one – all topics for consideration affect and interest the patient community. They should not be excluded from any of them.

4.17 Connected with this observation is the importance of understanding the full range of blood borne pathogens with which those exposed to blood and blood products may become

infected. HIV and hepatitis C are merely examples of these. Others include hepatitis B and vCJD.

4.18 The Inquiry requires to understand the context in which the HIV and HCV infections came about. The history of developing knowledge about the risks of infection, in particular of transfusion hepatitis from pooled products, were understood well before the emergence of Non-A/Non-B hepatitis or HTLV-3. Therefore, the Inquiry should consider both the historical context in which therapeutic and political decisions were being made. It is within that context and in light of that knowledge that the Inquiry must determine the question of whether transfusions and blood products were as safe as possible in response to the known risk of infection and if not, why not.

4.19 Further, threat from viral infection should not be seen as a purely historic phenomenon. The subject matter of this inquiry may in a sense be an historic but its relevance in a world where pathogens continue to emerge remains.

**The need to see things from the patient's perspective**

4.20 The NHS should aspire to minimise to the lowest level possible the risk of viral infection to its patients. Its patients are the ultimate recipients of those products as opposed to the donors from whom whose collections they were created.

4.21 In producing and using its products, the patients should have been and be at the forefront of the NHS' decision making throughout. If ever they were *not*, that requires to be uncovered.

4.22 The ultimate patients should have been and should be informed and their opinions should count in that process. If ever they were *not*, that requires to be uncovered.

4.23 The testimony we have heard from those whom we represent is that patients were not kept informed. They were not properly advised about the risks of the blood or blood products which they were given. Individuals must be held to account for this. Term of reference 10 must be fully investigated.

4.24 The extent to which informed consent was not obtained to treatment regimes in light of risks inherent in the products must be determined by the Inquiry. This is covered by terms of reference 1(d) and 6.

4.25 The attitude towards patients also extended to the failure to inform the patients that they were being tested and monitored for the evidence of infection. They were not told then they became infected, even with viruses which were known to be easily transmissible (terms of reference 7(a) and (c)).

4.26 When eventually they *were* told, they were told in unacceptable ways (term of reference 7(a)).

4.27 Far from putting their "right to know" at the forefront of the process, it was not even considered to exist in most cases. When questions were asked, medical records were secreted and destroyed or redacted or filleted of any information relating to the circumstances in which they received blood and/or blood products which turned out to be virally contaminated.

4.28 All this has led to patients losing trust in the doctors upon whom they relied for their healthcare and others who have been infected by transfusion being unable to prove to the state why, with the result that they are deemed to be drug users and spurned, not helped. The reasons for all of this this must be uncovered. It can only properly be understood by looking at the diversity of the circumstances in which patients were kept in the dark and eventually informed of the truth.

**The need to counter medical complacency**

4.29 Reasons why blood was sourced and injected into patients from foreign, paid donors must be exposed, such as the products which infected boys with HIV at Yorkhill in Glasgow, when in other parts of the country such a practice was deemed fundamentally unsafe.

4.30 Also, complacency about the safety of blood domestically requires to be uncovered and analysed. The reasons for the infection with HIV of a cohort of haemophilia patients in Edinburgh with domestically produced factor concentrates has never been explained. Also:

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

- Why did doctors using whole blood for transfusion appear to know so little about the risks inherent in the products with which they had been provided to do their work, where it was clear that transfusionists appeared to be concerned about viruses being present in the donor pool?

- Why were patients, who had not received treatment before, not afforded the opportunity to benefit from developments in other parts of the country in viral inactivation, when it was known that exposure to Scottish products would inevitably infect them?

4.31 The extent to which it was acceptable or appropriate that the principle of clinical freedom allowed regional variation which has led to a sense of postcode lottery must be examined. This applies not only to the treatment of patients by clinicians but also to the means by which blood was collected and blood products made available.

4.32 The issue of communication also arises in the area of the development and sharing of knowledge relating to practices such as the collection of blood from prisons, the means by which known high risk donors were excluded from blood collection sessions where inconsistent approaches undoubtedly led to patients becoming infected (term of reference 1(e)).

4.33 The subject of testing blood for viruses is another area of importance for the Inquiry, in particular relating to hepatitis C, though also relating to HIV. The Penrose Inquiry has to an extent uncovered factual material relating to the introduction of testing and the interactions between the medical world and government in that regard. In particular in the area of hepatitis C, the failure to introduce surrogate testing and the reasons for the late introduction in Scotland of anti-HCV testing, the role of commercial interests in this area and the interaction between those making decisions in Scotland and at a UK level are matters which merit careful analysis.

**The need for communication to be built into the regulatory framework**

4.34 Knowledge of risks requires to be communicated for the benefits properly to be drawn from scientific developments. The Inquiry must pay attention to the issue of communication - between the clinicians and the patients and their families, clearly, but also (i) between government and the medical profession, as well as (ii) between different branches of that profession, such as haematologists and transfusionists or regional centres

and local hospitals (iii) between agencies in different part of the United Kingdom and (iv) between professionals with a developed interest in the risks of blood and blood products and other colleagues using them in other medical settings.

4.35 Connected to this is the extent to which the legislative regime relating to notifiable diseases operated effectively to prevent the spread of infectious disease from blood or blood products within its reference period. This all forms part of term of reference 1(a) to (c), (e), (g), and (h) as well as term of reference 5(a)).

**The consequences for those infected and affected**

4.36 The public importance objective of the Inquiry of course requires to be borne in mind and rightly deserves consideration by you, Sir. However, it would be wrong for me not to emphasise the fact that we represent real people who have been affected by this disaster.

4.37 The *full* extent of the consequences of infection in the victims of this disaster needs to be understood. In particular the impact on the mental health of those infected and their families requires to be understood fully. Individual cases need to be looked at in this regard to understand this aspect. The particular impact upon those multiply infected with repeated exposure to infection through pooled blood products, for example to multiple genotypes of hepatitis C, is poorly understood and needs to be considered.

4.38 The financial consequences which they have suffered have been rightly included in the terms of reference as any inquiry which did not consider the extent of the effects on people's lives in this way would be remiss. We will say more in due course about what we would wish the Inquiry to recommend in this regard but our position is that established alternatives available including the legal system are unlikely to be suitable for adequately and fairly dealing with these losses given their historic nature which gives rise to evidential and legal difficulties as well as the lack of information which has been available to our clients over the years. Those who have benefited in Scotland from the *ex gratia* financial assistance which they have been afforded, in particular in recent years, see this as a step in the right direction. This does not go far enough, as we will come on to discuss. The Inquiry must understand fully the extent to which lives have been ruined, families destroyed and hope obliterated in order to inform what we as a society would deem to be an appropriate response.

4.39 In a recording taken as part of an oral history project curated by the Royal College of Physicians into the *Early Days of the Aids Epidemic*, one former consultant haematologist is recorded as making the following remarks among others:

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

4.40 These remarks are symptomatic of, frankly, a disgraceful attitude taken by a number of medics who see those, like our clients, who want answers and seek redress as "ungrateful" for what was done for them and who would now seek to blame *them* and stigmatise them for seeking to call those doctors to account. This kind of attitude needs to be called out and condemned by this Inquiry.

## 5. PROCEDURAL EXPERIENCES AND EXPECTATIONS

5.1 One important message which emerges from the clients whom we represent and, in particular, from their experiences of those of them who participated in the Penrose Inquiry is the need for a process such as this to provide real engagement.

5.2 It is all too easy for people to appear to care about their plight but what they need is the opportunity to engage properly with the discussion, to understand it and to feel that at every turn their voices have been heard.

5.3 One means by which this ambition may be frustrated is by imposing unrealistic procedural expectations and limitations on those for whom this inquiry is primarily designed. In this regard, we have the following views, again based in part on the Penrose experience.

### The clients as *participants* in the Inquiry

5.4 The clients whom we represent can, of course, tell their own individual stories. The ability and willingness of some of the clients, however, to perform a much wider function should not be underestimated or undervalued. Many have spent years, trying to uncover the truth of how they or their loved ones came to be infected. Some have dedicated their lives to that goal. Such people should, we suggest, be looked at as a positive resource upon which the inquiry can and should draw. They understand the long and complex background over many previous decades.

5.5 However, in order for their numerous voices to be heard, the Inquiry must afford these core participants the ability to be heard and to participate. This means that the procedure

of the inquiry must be suited to its objectives. In particular, legal representation must be funded such to enable it to be fully informed and engage fully with the process. Real opportunity and proper and adequate funding must be provided for the core participants to communicate effectively with their lawyers in meetings, with each other in forums and with the Inquiry throughout.

5.6 The Inquiry has seen fit to designate 250 of our clients as core participants and grant them the right to legal representation. This means that the Inquiry accepts that they have something of value to add to this process. Funding must be made available well in advance to allow a proper opportunity for all of their voices to be heard. Meetings which we have been able to hold with some of them identify common themes, but we are struck by the diversity of experience and points of view. Our clients have already represented to the Inquiry that an absence of proper funding will in their view hinder the proper engagement with the inquiry which they expect and to which they are entitled.

**The role of the lawyers for the infected and affected**

5.7 We as the lawyers engaged on their behalf fully accept that we have a professional responsibility to ensure that the public purse is not wantonly or unnecessarily depleted.

5.8 We underline therefore that we will only do such work in relation to this inquiry which on our professional responsibility and in accord with our professional ethics, we judge is necessary and reasonable to ensure that our clients' interests are protected and furthered.

5.9 And it is our intention only to come to and cover such of the inquiry hearings as are actually relevant to our clients' interests and for the level of that legal cover to vary depending on the importance to our clients of the matters covered. Our responsibility to the public purse means that we intend that our presence before the inquiry to be targeted and proportionate.

5.10 Our clients' interests are *not* being furthered if the role of the lawyers who represent them is restricted to clocking in, sitting passively and mutely day in and day out at each and every public hearing this inquiry may hold, regardless of the topic, doing nothing but watching the clock, and calculating their earnings for that day or week as the minutes tick by and mount up to reach a 60 hour maximum. That is *not* a role which either we or any of the Thompsons team are willing to play. If that is the kind of role which the Inquiry envisages for us, then I personally am not interested in playing it. It would be a betrayal of the trust which has been shown to us by our clients in asking us to represent them.

5.11 Instead, our clients want our role in this Inquiry to be active and collaborative. The fact that the legal team and many of the clients comes with the experience of Penrose under their belt means that we bring to this Inquiry a wealth of acquired experience, expertise and knowledge. In that sense we provide a resource which the Inquiry team can and should draw upon, the better and more efficiently for at least some of the Inquiry's aims to be achieved.

5.12 We see that much of our work may be in assisting the Inquiry in the investigative elements of its work. We accept that, in accordance with the Inquiry's own concerns and duties to ensure that the public money with which it has been entrusted is properly expended, we require to set out what work we wish to do, explain to the Inquiry why it is reasonable and necessary in the circumstances and vouch that it has indeed been done. We are happy too that there should be full transparency and regular publication (with full detailed breakdown of recipients and reasons) of just how and what money is being expended by the inquiry.

**The need for the Inquiry to maintain the trust and confidence of the infected and affected**

5.13 But we expect our professional judgment on what and how much work we need to do for our clients to be respected by the inquiry. This Inquiry cannot work if it fixes rates of pay at the lowest it thinks it can legally get away with, or if members of the Inquiry team think it within their budget maintenance remit to purport, without good reason or proper justification, to overrule our professional judgment on such matters. If the Inquiry treats our professional judgments on what work we consider to be *necessary* and/or as to how as to long this work will take as simply opening negotiating bids, then this Inquiry will succeed only in alienating those whom it professes to put front and centre. The infected and affected whom we represent will lose faith.

5.14 All of the Inquiry's efforts will come to naught unless it maintains the trust of the infected and affected. That will not happen unless they feel that they are being given a fair crack of the whip and that their designation as core participants is not some exercise in tokenism.

5.15 This is *their* inquiry. *They* want it to work. *They* want it to succeed. And they want we whom they have instructed to act for them, to hold the Inquiry to account, to ensure that it does not shy away from some of the difficult but essential issues before it, to hold the inquiry to answering all the questions which the Inquiry has been tasked to consider under

the terms of reference. The Inquiry needs to be aware of how high the stakes are in this regard.

5.16 If the Inquiry is to work and fulfil the justified expectations of our clients and live up to the trust and faith which *they* have placed in it, it needs to conduct itself in a collaborative manner with them and with their legal representatives. Our clients are not passive spectators of, or officious by-standers at, this Inquiry and they will not be treated as such. If our clients are to have confidence in this Inquiry and the conclusions it may reach, the Inquiry has to show that it trusts them and those who represent them to work together to achieve the Inquiry's aims and fulfil its terms of reference and bring at least some degree of closure which has been for so long denied our clients by the manner in which officialdom, the establishment in its myriad forms has treated them.

**Discovery: the need for full and timely disclosure of documents and evidence**

5.17 Arising out of experiences with the Penrose Inquiry, we would emphasise that documents released to the core participants must be released with time for their content to be considered properly. The pace of the Inquiry must be such that it enables matters to be investigated thoroughly.

5.18 You have, Sir, received, it would appear a number of representations suggesting that the infected and affected are keen that the Inquiry should be concluded quickly – there are many good reasons as to why that would be a laudable aspiration. However, this is too important for the extensive materials to be rushed through – for our part we would prefer thoroughness over speed.

5.19 Further, the Inquiry must not underestimate the scale of its task. We consider it important that the Inquiry does not start with preconceptions about where the evidence will lead but be led by what it discovers. This is an *inquiry*, not an exercise in confirmation of preconceived notions or expectations. It must approach the evidence with an open mind and carry out its investigation fully, fairly, and fearlessly. Factual witnesses must be used as exactly that – sources of evidence as to what happened, not sources of analysis of their own actions.

5.20 We consider that the Inquiry must take time to ensure that documentary evidence such as exists is considered. The Penrose discoveries must be recovered in their entirety, not just those documents which were released to core participants (less than 5% of what was

circulated publicly). Further advantage can be taken of documentary discovery exercises conducted by other inquiries such as the Archer Inquiry.

5.21 The Inquiry must use its powers to access original paperwork from the time of the infections as well as subsequent paperwork relating to the disaster, a comprehensive list of which was submitted to the Penrose Inquiry as part of our clients' response to the terms of reference consultation at pages 7 to 8, in particular the warning letters issues by Penrose as part of the Maxwellisation process, and the responses received thereto. The cover-up must not be permitted to succeed. An exhaustive documentary recovery process is key to this as well as an inquiry into why records which existed at the time no longer exist. The work done by other inquiries in this regard will be a useful starting point.

5.22 And the Inquiry must as part of its remit use its powers to call those responsible to give evidence under oath before it. The history of the disaster and the need for transparency make behind the scenes discussions and decision making about oral testimony completely unacceptable, another key lesson from *Penrose*.

**The structuring of topics**

5.23 We suggest that, the structure of the topics which require to be examined should be considered fully and carefully in advance. Starting with the terms of reference, there appears to be a need to impose some sort of structure on the way that the inquiry will go about its work, allowing focus to fall on different areas at different times so that particular terms of reference can be examined and understood in detail. Simply embarking on a general journey through 50 years of evidence without that structure is unlikely to be successful.

5.24 In the Penrose Inquiry, the basic structure split the subject matter of the Inquiry into matters pertaining to HIV and those pertaining to hepatitis C and then into different time frames, recognising that at different times different things were happening as knowledge and technology advanced. The different considerations pertaining to infections as a result of blood products and as a result of blood transfusions as well as the different experiences of those communities require to be recognised structurally. Though some structure is likely to be essential, rigid adherence to it should not, in our view, result in important matters being missed or glossed over.

5.25 It will become apparent, we think, that there was geographical variation in approach and experience throughout the United Kingdom. It may be appropriate for the structure to recognise that different considerations may arise in relation to practices in different parts of the country. However, any such structure must not forget that the reasons for variation in approach in different areas will be an important part of the Inquiry's analysis. The Inquiry must therefore be careful not to look at different geographical parts of the country as if they were hermetically sealed from the others. We need to know:

- Why was a certain approach taken in one place when it was deliberately avoided in another?
- Who if anyone was responsible for the oversight and co-ordination of approach in the best interests of patients?

5.26 At this stage we have little insight into how the Inquiry intends to structure its investigations or its hearing of oral evidence. With these general observations in mind, we would be happy to be involved in assisting the Inquiry in arriving at how that structure might work best. We would suggest that, in general, expert evidence should be taken grouped together by topic and the relevant expert witnesses from like disciplines are heard concurrently, [3] allowing them to hear and come back on the evidence of other experts.[4]

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[3] cf CPR Practice Direction 35 (which supplements as from 22 November 2017 the Civil Procedure Rules 1998) on

> "**EXPERTS AND ASSESSORS**
>
> ,,,
>
> 11.4 Where expert evidence is to be given concurrently, then (after the relevant experts have each taken the oath or affirmed) in relation to each issue on the agenda, and subject to the judge's discretion to modify the procedure—
>
> (1) *the judge will initiate the discussion by asking the experts, in turn, for their views in relation to the issues on the agenda. Once an expert has expressed a view the judge may ask questions about it. At one or more appropriate stages when questioning a particular expert, the judge may invite the other expert to comment or to ask that expert's own questions of the first expert*;
>
> (2) after the process set out in (1) has been completed for any issue (or all issues), the judge will invite the parties' representatives to ask questions of the experts. Such questioning should be directed towards: (a) testing the correctness of an expert's view; (b) seeking clarification of an expert's view; or (c) eliciting evidence on any issue (or on any aspect of an issue) which has been omitted from consideration during the process set out in (1); and
>
> (3) after the process set out in (2) has been completed in relation to any issue (or all issues), the judge may summarise the experts' different positions on the issue and ask them to confirm or correct that summary."

[4] See too the survey on the practice in Gary Edmond and others "Assessing concurrent expert evidence" (2018) 37 *Civil Justice Quarterly* 344-366

**Examination of witnesses by or on behalf of the core participants**

5.27 We would counsel the Inquiry that it needs to take care to ensure that the infected and affected are able to ask the questions they want to ask. It may be easy for the Inquiry to reach the view that a certain line of questioning is uninteresting or irrelevant. However, in doing so the Inquiry must take care not to prejudge the importance of material which that line might uncover or underestimate the value of the questions simply being asked in the first place.

5.28 Part of the purpose of the Inquiry is to allow questions which are important to those infected and affected to be asked and answered. It is not your inquiry or our inquiry. It is their inquiry. You need to call the witnesses whom they think should be called before you.

**Compellability of witnesses and evidence on oath**

5.29 One of the great advantages of this Inquiry, by way of example, is the fact that it is a UK inquiry. The Inquiry will therefore have the power to call individuals as witnesses from throughout the UK to give evidence. Matters pertaining to Scotland with which this Inquiry is involved come from a pre devolution political landscape. Though matters pertaining to healthcare were dealt with by the Scottish Home and Health Department within the Scottish Office, decisions made at a political level were made at Westminster. This meant that those responsible were on occasion not compellable as witnesses within the context of the Penrose Inquiry. That these individuals are examined as to what they did and why and, where appropriate, held accountable for their failings is essential.

**Transparency**

5.30 Where the substance of the contaminated blood disaster meets the procedural requirements of this Inquiry into it is in the area of transparency. Patients will tell the Inquiry again and again that they were, both around the time of their infections and subsequently, kept in the dark about what had happened to them and how it had happened. Secrecy on the part of government officials and medical professionals has led in many quarters to suspicion and mistrust on the part of the infected and affected. We have already touched upon the importance of investigating and exposing the extent of the cover-up. The work of the Inquiry must be conducted in public and not in secret behind closed doors. The investigation and decision making processes must be transparent if the Inquiry is to fulfil its terms of reference and objectives.

**The proper exercise of the Inquiry's investigative and inquisitorial functions**

5.31 That the Inquiry has an investigative and critical function must be at the forefront of the way that it conducts its business. In specialist technical areas it is all too easy to allow the process to be guided or captured by experts or clinicians, many of whom have a vested interest in the outcome.

5.32 As we have already said, the Penrose Inquiry stands as a useful starting point to the work of this Inquiry in that it has compiled much of the factual and scientific material necessary for the inquiry to start its work.

5.33 That is *not* to say that the Penrose Inquiry uncovered all the facts of the scandal. In many areas it has not conducted a thorough factual investigation. We have touched upon some of its flaws already. What the Penrose Inquiry certainly has *not* done, we would suggest, is challenge the account given by government and the medical profession about what happened.

5.34 Certain key figures have again and again trotted out the same line. Their position on the facts is well known. What about those who have not been asked? The nurses, for example, who sat with the patients?

5.35 This Inquiry requires to challenge what is said by those who may bear some responsibility and what has been done in the name of the public. It requires to ask itself what happened, why it happened as well as what ought to have happened, what could have been done better and why. Ultimately, those who were responsible require to be held accountable.

**The role of the expert panels**

5.36 Finally, there is the decision making function of the inquiry and how that will work. You have, Mr Chairman, received representations made on behalf of our clients encouraging you to consider sitting with a panel alongside you to assist you in your given function.

5.37 The Penrose Inquiry experience led many of our clients to take the view that one person making all the decisions posed the risk of the inquiry's focus being taken away from the people whom it was meant to serve. It was considered that that risk would be offset, to a

certain extent at least, by a panel of decision makers whose different experiences and backgrounds would allow more balanced decision making.

5.38 As we understand it, your view is that that you would prefer to sit alone and that the procedural mechanism of expert groups would in some way address the concerns which have been expressed in this regard. Whilst our preference remains for a panel, we wish to be reasonable and for progress to be made.

5.39 While we recognise that there is a need for the Inquiry to be assisted by independent professionals in various areas so that the complex subject areas in which it will become involved are understood properly, we still have some concerns at present about just how the expert groups are going to work in practice. Though the concept, as we understand it, was originally conceived in response to our clients' request for a panel of decision makers, we are as yet unclear just what role the expert groups will play in that regard.

5.40 If we understand matters correctly the idea of the expert groups is to provide you as the Inquiry Chair with neutral scientific advice, to offer explanation on technical issues arising in the inquiry and effectively provide the Chair with the opportunity for a "tutorial" or "teach-in" (such as occurs for some judges in some Patents cases [5]) and to assist the Chair with the technical detail, terminology and complexity of the various subject-areas you will require to master if the Inquiry is going to conclude with useful and realistic final recommendations

5.41 Their involvement, it seems to us, seems more evidential (in that they will give evidence about areas within their expertise) and investigatory (as they will suggest questions to be put to witnesses insofar as their evidence pertains to areas their expertise) than in the decision-making realm. We note that in your update you have said:

> "The reports of the groups will, as evidence, be fully open, accessible and transparent. Where there are significant disagreements among the experts, these will be tested, explored and challenged openly in the public hearings."

5.42 But what if there is a consensus among the experts, the "received wisdom" but it is not one which we or our clients consider to be well-founded. Is there any opportunity for

[5] See e.g. *Electromagnetic Geoservices ASA v Petroleum Geo-Services ASA* (ChD) [2016] EWHC 27 (Pat) (Ch D) [2016] 1 WLR 2353 per Birss J at para 31 and *Electromagnetic Geoservices ASA v PetroleumGeo-Services ASA: Practice Note re teach-ins* [2016] EWHC 881 (Pat) (Ch D) [2016] Bus. LR 503

public challenge or examination of experts? [6] It has to be borne in mind that the experience of many of our clients was precisely that it was the then "received wisdom" gathered from a "complacency of experts" (if that is the correct collective noun) which resulted in their suffering the harms that they did and so much of their lives since they have been infected has been one of challenging received wisdom and then medical consensus of what was "best" for them. To create expert groups charged with formulating a consensus among themselves to inform the inquiry chair risk resulting in yet further disempowerment of the infected and affected represented before the inquiry.

5.43 The precise function of these expert groups will, we would suggest, require to be more fully thought about and consulted upon more fully. We are unaware of whether the intention is that the groups will remain involved after the evidential stage of the process and, if so, to what extent they will influence your final report. This is an important issue if the Inquiry's process is to be transparent and fair [7] and to remain one which fully engages our clients concerns and interests. So we reserve our judgement on this proposal until we have heard more on it. On the assumption that this can be clarified, we would wish in any event to have some involvement in the selection of the individuals to sit on the groups.

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[6] cf *Owners of the Ship Bow Spring v Owners of the Ship Manzanillo II (Practice Note)* [2004] EWCA Civ 1007 [2005] 1 WLR 144, paras 57-65, on the need for fairness. Clarke LJ said:

> 58. Both the common law and the Convention regard fairness as including the need for the court to know, before it reaches a conclusion, what the parties have to say about the issues and the evidence which goes to them. As the European Court of Human Rights put it in *Krcmar v Czech Republic* (Application No 35376/97) (unreported) 3 March 2000, para 40:
>
> > 'The concept of a fair hearing ... implies the right to adversarial proceedings, according to which the parties must have the opportunity not only to make known any evidence needed for their claims to succeed, but also to have knowledge of, and comment on, all evidence adduced or observations _led with a view to influencing the court's decision.
>
> 59. Where the court has evidence from an expert who has not been called as a witness by either party_.... the principle needs to be adapted to the procedure. Its effect is that any consultation between the assessors and the court should take place openly as part of the assembling of evidence. *Because the judge is not bound to accept the advice he receives from the assessors ... the parties are entitled to an opportunity to contend that he should or should not follow it. In many, perhaps most, cases the questions and advice taken together will be susceptible of little or no argument that has not already been directed to the issues which have prompted the questions. But fairness requires the opportunity to be given.*"

[7] cf *Halliburton Services Inc v Smith International Ltd.* [2006] EWCA Civ 1599 [2007] Bus. LR 460 per Chadwick LJ at para 21 (emphasis added):

> "We should not deny ourselves the assistance which the special adviser can give in helping us to understand the expert evidence given at the trial; in helping us to consider whether there are grounds to think (from the manner in which he has dealt with that evidence in his judgment) that the judge has failed fully to understand that evidence; and in helping us to evaluate the factual conclusions which the judge has reached on the basis of that evidence. *But we must keep in mind the overriding requirement of fairness. And we must keep in mind that it is our task- and not that of the special adviser - to decide the appeal.*"

## 6. THE FUTURE

6.1 As we have already said, all amongst those whom we represent share the fact that they are the victims of this disaster. Their stories are different but they reflect common themes. These themes exemplify the best and the worst of who we are as people within the communities of the United Kingdom. They demonstrate our humanity and at times our lack of it. The examination of their stories, we hope, will lead is to understand better how we provide healthcare in this country and how we aspire to provide in the future.

6.2 It would be easy to see this subject matter of this inquiry as being one which is predominantly historic in nature - its focus will be on the 1970s and 80s. Many of the key players in medicine, science and government have long since died. The consequences of the contaminated blood disaster, however, live on, as does its capacity to inform future practice, support and attitudes. There are many areas in which we anticipate that the inquiry will be able to affect current and future life for the better. In particular, as far as our clients are concerned, the following are key outcomes which we hope the Inquiry can facilitate.

### Truth and justice

6.3 There requires to be an opportunity for truth and justice for the infected and affected – and perhaps ultimately reconciliation between them - and those responsible for the infections, both from the NHS and from our Governments.

*Apology and acceptance of responsibility*

6.4 The experience of the Penrose Inquiry was that doctors and government used the Inquiry as an opportunity to defend themselves, indeed to use the process as a platform to seek praise for their achievements. There was no sign of an apology from them, or much in the way of contrition or regret.

6.5 Whatever the outcome of its factual investigation, this Inquiry must, we think, constitute a platform from which bridges can be built between those whom we represent and the governmental and medical communities. There requires to be an apology for the harm done. It must be a specific apology for what precisely went wrong.

**Lessons to be learned for the future**

*No blood from prisoners*

6.6 We believe that the epidemiological evidence is clear that prisoners are at significantly increased risk of transmitting blood borne infections and would therefore represent an unacceptably high risk to blood safety when the next blood borne infection emerges. The gift relationship is not possible when the donor is incarcerated. We support the conclusion that there should be an express and permanent ban on the use of blood or organs from prisons, borstals or other such institutions. More generally there has to be constant vigilance and proper safeguards against the temptation to source blood and/or blood products based on solely or even primarily financial parameters.

*Safety first*

6.7 We believe that the evidence will lead to the conclusion that the interests of the ultimate users of blood and blood products should always be placed at the forefront of blood transfusion policy. The threshold for using a new blood test, including surrogate tests, to exclude donors is too high with too much emphasis placed on false positives reducing the blood supply. A transfusion policy should be introduced to address this. This will increase patient safety with any shortfall in the blood supply being addressed by recruiting more donors.

*Safety levy on big-Pharma*

6.8 Companies introducing new treatments to the UK should be required to pay into an appropriate financial vehicle, to be managed by the Government, to provide assumed liability financial support payments to any patients harmed by unforeseen damage from their products.

6.9 At the moment, the profits from successful treatments accrue to pharmaceutical companies while the costs of providing ongoing financial support falls to the taxpayer. This proposal would remove the financial incentive for institutional cover up and help ensure events could be examined quickly and relevant lessons learnt early.

*Duty of candour*

6.10 Patients and the advocacy groups representing them must be advised fully and frankly and at an early stage when any potential risks or problems with past, current or future treatments or products are identified. This duty of candour relating to products should be extended from organisations to individual healthcare professionals via appropriate professional guidance. This would allow patients to be involved as equal partners in the reflective practice of clinicians. Both healthcare professionals and patients should be encouraged to voice concerns without fear of prosecution, reduction in service provision or damage to career prospects.

6.11 New legislation has recently been introduced on this issue. For example in Scotland Part 2 of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016 introduced the concept of duty of candour within the NHS in Scotland, and its associated Duty of Candour Procedure (Scotland) Regulations 2018 came into force on 1 April 2018. Similarly the Care Act 2014 and the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 have introduced similar provision in England, where additionally the Care Quality Commission is also able to initiate and pursue criminal prosecutions in certain circumstances. This is a point which will be considered in more detail at a later stage in the Inquiry but shows at the very least the move towards greater transparency and candour from a regulatory perspective: see e.g. https://www.cqc.org.uk/sites/default/files/Duty-of-Candour-2016-CQC-joint-branded.pdf. The Inquiry needs to ensure that these provisions are not simply theoretical obligations but are being properly embedded in everyday clinical practice.

*Security and reliability of medical records*

6.12 We believe that the Inquiry will uncover evidence of medical records being amended or destroyed. All patient records should be held electronically for all patients. These records should be accessible to patients and, once entries are placed in the record, it should not be possible to remove or amend them retrospectively other than on the patient's application to ensure that it is possible to remove incorrect entries such as false accusations of alcohol or drug abuse we mentioned earlier

*Informed and continuing re being the subject of medical research study*

6.13 We believe that the Inquiry will uncover that individuals were involved in medical research without their knowledge or consent. This is an unacceptable - and arguably now an unlawful - practice: see the *Oviedo Convention on Human Rights and Biomedicine* which the UKSC referred to and relied upon in *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 [2015] AC 1430 at per Lord Kerr of Tonaghmore and Lord Reed at para 80. See, too, the provisions of Article 3 and Article 8 of the Charter of Fundamental Rights of the European Union which provides as follows:

> **"Right to the integrity of the person**
> 1. Everyone has the right to respect for his or her physical and mental integrity.
> 2. *In the fields of medicine and biology, the following must be respected in particular:*
> *(a) the free and informed consent of the person concerned, according to the procedures laid down by law;*
> (b) the prohibition of eugenic practices, in particular those aiming at the selection of persons;
> *(c) the prohibition on making the human body and its parts as such a source of financial gain*
> (d) the prohibition of the reproductive cloning of human beings.
> ....
> *Article 8*
> **Protection of personal data**
> 1. *Everyone has the right to the protection of personal data concerning him or her.*
> 2. *Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law.* Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.
> 3. Compliance with these rules shall be subject to control by an independent authority.

6.14 There requires to be a clear research subjects' rights framework which makes it clear to any patient involved in research what their rights are to information about risks, to withdraw from research, to see the results of any tests, to be made aware of any published materials relating to their case and to be assured that no blood or tissue sample (including historic samples) should be used for any purpose for which the patient has not given full and informed consent (or their next of kin if the person is deceased). The contaminated blood and blood products disaster should be used as a case study in the teaching of the framework in medical schools.

*Patient safety and clinician autonomy*

6.15 We believe that the Inquiry will uncover evidence of individual clinicians being able to take decisions without oversight, based on individual preferences and also of situations where they were unable to act where they wished to do so. The desire to preserve clinical independence made political oversight ineffective. Too often clinicians were left to grapple with issues of public policy and, without appropriate political or organisational leadership

made inappropriate decisions. Improved political and organisational oversight and greater accountability is required.

## Caring for the infected and affected

*Follow up*

6.16 There requires to be long-term follow-up of the infected and affected. Anyone affected by the disaster should be able to opt into a long-term impact monitoring scheme. This would help identify physical or mental health impacts of the disaster and, particularly in the case of the multiply exposed, other potential pathogens. This work should take a broad and holistic view of impact and include educational and employment opportunities as well as deaths from all causes. This would help ensure that as yet unknown impacts of the disaster are identified as early as possible and where appropriate treatment and support provided. This should be supported by the provision of a psychiatrically trained social worker teams conducting home visits to ensure even the most isolated and unwell have access to these services.

*Psychosocial support*

6.17 There should be a national psychosocial support service in Scotland so that everyone who has been infected or affected by past treatments with contaminated blood or blood products in Scotland or impacted by the disaster gets the professional support they need.

*Full financial compensation for the infected and affected*

6.18 There requires to be a recognition that where those in need of the care of the state have been infected by the treatment that the state provided, the state has a responsibility to provide those infected and affected with full financial compensation in implementation of its social responsibility for its citizens.

6.19 Support schemes require to be extended to provide full support to those infected and affected. Though such schemes in Scotland go some way towards achieving this, the current schemes do not compensate individuals for the decades of past losses which they have suffered in years when government refused to recognise their plight. Transfusion records, or lack thereof, precluded some people from even accessing the support charities like Skipton and also the Scottish support scheme. So these people can't even get on the ladder.

6.20 The existing schemes require to be expanded to recognise the lost decades, as well as to understand the extent of the impact on those infected chronically. The affected, including widows and children also require support, including financial support. All support should be exempt from taxation and any negative impact on benefit entitlement, i.e. not included in assessing any other state benefits available to them. The support needs to recognise real loss and not just award arbitrary sums.

6.21 The UK Government should set up compensation panels to provide appropriate, tailored compensatory packages. The compensation should aim to provide *all* victims (both those who are the primary infected, and their spouses, partners and children inextricably affected) with the level of compensation they would receive under civil law. That the measure of appropriate compensation is full civil law damages. That is the regime which applies in Ireland. Why should those in the UK who have suffered from the contaminated blood disaster receive anything less than would be awarded in Ireland?

6.22 Financial products such as insurances are often not available to the infected - the Government should work with providers to create bespoke products, underwritten by the Government. The victims of the contaminated blood disaster should not at any time have to endure the indignity of continually providing evidence of their incapacities and detriments that were inflicted by the state to the various agencies whose assistance they require.

6.23 The resulting financial support programmes for infected and affected persons, including widows and widowers, should be completely separate from the funding for treatments and interventions. It is impossible to predict the future requirements and associated costs as new treatments are required or developed, so this should be provided for separately.

*Lifting of time bar re court actions*

6.24 If it remains necessary to do so, those infected and affected require to have recourse to the courts to receive damages for their losses. The particular circumstances in which these losses were sustained should give rise to rules relating to time bar being lifted, as has been the case in Scotland in relation to claims based on historic child abuse: see Limitation (Childhood Abuse) (Scotland) Act 2017. This is the other side of our recommendation for a panel to assess full compensation. If there is disagreement between the assessors and

the victims' representatives, the victim should be able to go to court to effectively adjudicate on the disagreement. This mirrors what happens in Ireland. It also reflects past practice in other compensation schemes set up, for example in relation to the chronic bronchitis and emphysema developed by miners in the course of their employment. If compensation could not be agreed under these schemes, the victim could raise proceedings without facing a limitation argument.

*A secure funding stream for charities representing and supporting the survivors*

6.25 The consideration of inherited bleeding disorders and the consideration of infection have become almost inseparable. Nowhere is this more evident than in the work of the charitable bodies whose work involves assisting with matter relating to the disorders but also inevitably with the infections with which that community suffers.

6.26 A secure funding stream should be established for inherited bleeding disorders charities in Scotland with a similar stream for those charities supporting transfusion infected and affected patients. This should provide a minimum level of unrestricted funding to secure the long-term future of patient support and provide access to restricted funding to provide targeted, project-based information and support to those affected by the disaster. These organisations provide invaluable advocacy services to maximise the representation of people in these communities. No decisions about the treatment or care of people with inherited bleeding disorders or transfusion victims should taking without the active involvement of that community.

**Medical research**

6.27 We believe that the Inquiry will uncover many areas where further medical research is required to understand fully the implications of the contaminated blood disaster for its victims. The UK Government should establish a research fund to support work in these areas. We believe that this should include valuable research into the following areas:

- Are there any clinical implications of being repeatedly infected with multiple genotypes of hepatitis C?

- Does multiple exposure have an impact on the likelihood of 'clearing' the virus naturally, immune response fatigue, the success rate of treatment or prognosis and if so, why?

- Do the long term sexual partners of people with an inherited bleeding disorder, who have been exposed to contaminated blood or blood products experience an elevated rate of any condition or disease?

6.28 Almost all of the evidence in this field, for example in relation to the primary and associated health impairments of viral infection, are based on study cohorts that include all infected people without distinguishing between the whole population and those who have been infected by blood or blood products. Are there any unique characteristics or issues for people whose viral infection was a result of contaminated blood or blood products compared to the much larger groups of people whose infection was due to unsafe lifestyle behaviours and choices?

## 7. CONCLUSION

7.1 The 250 individuals who have asked us to represent them have entered this inquiry process, their inquiry process, with confidence that it can and the hope that it will deliver on its terms of reference and meet the objectives we have detailed in this statement. If the Inquiry is not about the infected and affected whom we represent, and others from around the country like them, who is it about?

*7.2* *They* are the people whom you need to put at the heart of this process, in a meaningful way. *They* - and we as their representatives - are committed to working with the Inquiry to ensure that the outcome of this process meets all of the objectives which we have outlined above, where other investigations, bodies and Inquiries have failed. Their commitment to do so is based on their legitimate - and, we hope, well-founded - expectation that they will find full investigation, transparency, respect, trust and honesty here, where they have not found it elsewhere.

*7.3* May I say commend you Sir for your opening remarks that at this preliminary hearing in which you recognised and celebrated the fundamental dignity, the perseverance, the sheer courage of the infected and affected. May I also say that what those who we represent have seen here, has given them hope and, indeed, cautious optimism.

*7.4* We therefore look forward to working with the Inquiry in a fully collaborative and active way with a view to achieving our common objective of fulfilling the terms of reference and bring justice to those who have died, and to those whose lives have been unutterably altered and burdened by this scandal by illness and bereavement.

*7.5* It is to those lost lives, to those stolen lives, that we commit ourselves.

**AIDAN O'NEILL QC**
**JAMIE DAWSON**
**KIRSTEN SJØVOLL**