INFECTED BLOOD INQUIRY
OPENING SPEECH

Sir, those I represent want three things from this Inquiry

FIRSTLY, THEY WANT THEIR STORIES HEARD
SECONDLY, THEY WANT THE TRUTH
THIRDLY, THEY WANT JUSTICE

Clients

1. My name is Lloyd Williams QC, together with Mr Christian Howells and instructed by Watkins & Gunn Solicitors, we represent 109 core participants of whom 106 are infected and affected individuals from Wales, Northern Ireland, England and Scotland. They are largely concentrated in Wales and Northern Ireland. I am pleased to say many of them attended either yesterday or today.

2. One other individual we represent is Julie Morgan, a member of the Welsh Assembly and a founding member of the **Cross-Party Group in the Welsh Assembly on Haemophilia and Contaminated Blood** a group that has given support and encouragement to those who have been infected by contaminated blood and their families.

3. We also represent Haemophilia Wales and Haemophilia Northern Ireland, charitable organisations that represent the interests of their members who are largely, but not exclusively, haemophiliacs and their families (or family members of deceased haemophiliacs) who received infected blood products in the treatment of their conditions. Their membership also includes people who received infected blood transfusions and their families. They are umbrella organisations and through them we represent the interests of many others.

INTRODUCTION

4. We know that you are anxious to get into the substance of the Inquiry as soon as possible, but as a result of this we find ourselves in a somewhat curious position being permitted to make an opening statement when we have not seen a single witness statement nor have we had sight of a single disclosed document. This has the happy advantage that what I'm about to say represents the unvarnished views, opinions and wishes of those we represent.

5. As we understand it, we have been invited to address the Inquiry on what our clients think are the important issues which they wish this Inquiry to focus on. In the time allowed we have consulted with such of our clients as have been available, but in particular Haemophilia Wales and Haemophilia Northern Ireland.

6. At the outset I should make clear that unless the situation requires it, I will not call those we represent the infected and affected but rather I will call them the victims because that is how those we spoke to regarded themselves and that is how they wish to be addressed in this opening statement.

7. Further, unless the context otherwise requires it, I will refer to blood and blood products simply as blood products.

Taking the three points in turn.

THEY WANT THEIR STORIES HEARD

8. A word of warning, one should not underestimate the sheer anger felt by the victims. Their feelings are as raw today as they have ever been.

We were presented with a stark example of that during our consultation with a group of victims. A woman, whose two brothers had died having been infected with Hepatitis C, she cut through the discussions and stated in a firm way that she regarded her two brothers as having been **murdered -** not everyone of those we represent would use that word, but would all would share the anger she felt at their wholly unnecessary and avoidable deaths.

9. The victims want their stories heard, and what appalling stories they have to tell. They are the wholly innocent victims of catastrophic failures on the part of American drug companies, Government (using that term in the widest sense), the providers of health services and the medical profession. Failures which have condemned thousands to an early death and many more thousands to lives dominated by ill-health, fear, anger and impoverishment.

10. The victims feel it is important at this stage that the Inquiry is given a flavour of how their lives have been destroyed. There are a number of themes that need to be considered. They are:

    a. The initial shock of infection;
    b. The ill-health associated with infection which, in many cases, compounded the ill-health associated with the pre-existing haemophilia;
    c. The treatment they received for Hep C - Interferon - itself could have severe side effects, sometimes resulting in death. Side-Effects which were well known to the medical profession but of which their patients were not informed;
    d. The various forms of treatment they have received to deal with the damage caused by Hep C / HIV, such as liver transplants that many underwent to remove cancerous livers directly caused by Hepatitis C;

e. The combined effect of Hepatitis C and HIV for those unfortunate enough to have been infected with both viruses;
f. The stigma attached to the two conditions and ostracism from the community of the victims and their families;
g. The shock of finding out that their infection could have been avoided;
h. The anger, resentment and bitterness they feel towards those whom they trusted and were entitled to trust;
i. The financial devastation that followed infection;
j. The ruined family and private lives of the victims;
k. The guilt that the victims feel about potential infection of their loved ones and the burden they feel they have become to their families;
l. The guilt that the wholly innocent parents feel for not questioning the treatment which was provided to their children and for being the ones who administered the contaminated blood products at home.

11. This is not an Inquiry simply looking back into the past, its an Inquiry looking into the here and now and into the future and the victims want to make it clear in their evidence that they have suffered not just for the last 40 years but they suffer now and they and their families will continue to suffer. Indeed, some infected by contaminated blood don't even know the suffering they are about to face. One of the appalling features of this disaster is that there may be thousands of people who are unaware that they were exposed to contaminated blood products and that they have contracted Hepatitis C and/or HIV.

12. I now turn to some examples foreshadowed earlier:

a) A 17 year old lad suffering from Haemophilia whilst attending hospital alone for one of his regular appointments was told by the treating doctor that he had HIV. He was told not to tell anyone about it, not even his mother. He was told he had about 18 months to live. He regarded it, as many did at the time, as a death sentence. He was not provided with any support or counselling whatsoever and he was unable to confide in anyone because of the stigma attached to HIV. Thereafter, he took to the excessive consumption of sleeping tablets together with morphine and other drugs to numb his feelings. He was regularly admitted to hospital for treatment for Haemophilia where he saw other Haemophiliacs, his friends, dying from AIDS. He had a nervous breakdown and was admitted to a psychiatric hospital. Later he was informed he had been infected with Hep C and was treated for cirrhosis of the liver, which turned out to be a misdiagnosis. Notwithstanding his original prognosis, he is still alive today. As a result of becoming infected with HIV and Hep C, the way in which he was informed that he had contracted those diseases, the complete lack of counselling provided and the treatment he has undergone for those diseases, he regards his life as ruined. He and his wife live a hand to mouth existence, having to apply for financial support (or as he put it, carrying around a begging bowl); such applications are usually turned down;

b) A now mature lady was given a blood transfusion many years ago during the birth of one of her children. That transfusion was infected with Hep C. She developed cirrhosis of the liver and later, liver cancer and has undergone two liver transplants. She has suffered from other very serious ailments as a result of the transfusion, which meant that a considerable proportion of her life has been spent inside the hospital doors so that her husband too, has spent long periods of his life inside various hospitals in Northern Ireland and London whilst at the same time trying to raise and support their children. Consequently, the landmarks of everyday family life that people take for granted, such as weddings, birthdays and family parties, became extremely difficult for this couple to attend. She has been unable to go on holiday because of the cost of insurance and the fact that she has to be within 3 hours of a transplant hospital. She has been in a long and happy marriage with her husband but when diagnosed with Hep C she was questioned about how many sexual partners she had and whether she was a user of illicit substances. Notwithstanding the severity of the illnesses she has suffered, in some ways the most significant effect upon her is the overwhelming sense of guilt she suffers. Guilt because she fears that she has passed on the infection to her children and grandchildren, who are currently being tested for Hep C. Guilt because she feels that she has become a burden to her husband and the family. When her condition became more widely known, her daughter was bullied and ostracised at school. For most of her life, she felt that she was the only one who had suffered in this way, until the Inquiry was announced;

c) A middle-aged man who suffered from mild Haemophilia underwent an elective minor procedure to his eye as a 14 year old boy. During this procedure he was given a blood transfusion. Neither he nor his parents were given any warning about the risk of contaminated BPs and so were deprived of the opportunity to make an informed decision as to whether to proceed with the surgery with full knowledge of the risks. He developed Hep C. Symptoms only became apparent in his 30s by which time he was married with children holding down a responsible job. As a result of him becoming unwell, his wife divorced him, he became estranged from his sons and he hasn’t seen them for over 20 years. He developed liver cancer and has had two transplants. When at a hospital in Newcastle for unrelated healthcare, he was asked to meet a Consultant in a side-room. He was informed, for the very first time that a pint of blood that he was given when he was 14 years old during that eye surgery was infected with Hepatitis C. The Dr who told him picked it up from a note contained in his medical records - but he was wholly unaware of it. He continues to try to work although suffering from serious medical complaints. He complains of unjustifiable difficulty in obtaining medical and dental treatment.;

d) His brother, also a mild haemophiliac, when a teenager suffered minor bleeding playing a game of football, he was treated with blood products resulting in Hep C. Neither he nor his parents were advised of alternative treatment that could have avoided or materially reduced the risk of contamination. He went on to develop cirrhosis of the liver. He is not critical of the subsequent medical treatment he received, but he does complain that for some time he was not allowed to see his medical notes. He recalls being invited to a meeting at the haemophilia centre with other haemophiliacs when they were asked whether they wanted to know if they had been infected with Hep C / HIV. It was apparent that his blood had been tested without his consent and that the HA and/or the doctors had know for some time of his contamination. He also received an unsolicited letter in the post asking the same question;

e) Recently a case came to light of a lady who contracted Hepatitis C as a result of receiving a blood transfusion in 1979 for rheumatoid arthritis. In 2010, she was hospitalised with septic arthritis in her hip. It was only at that point that a doctor suspected that her symptoms were caused by Hep C and tested her. Thus, she lived with undiagnosed Hep C for 31 years. She now has early onset dementia and it has been suggested that there is a link between the undiagnosed Hep C and dementia;

f) Two brothers, both mild haemophiliacs. One brother attended hospital with a bleeding nose which was treated with Factor VIII. However, that treatment did not stop the bleed and so his nose was cauterised. As a result of the treatment with Factor VIII, he contracted Hep C. The lack of appropriate advice and warning deprived him of the opportunity of avoiding treatment with Factor VIII. His brother, by good fortune, did not require treatment during that period and does not have Hep C. The selection of Factor VIII above all other treatments meant that the doctors were playing Russian roulette with his life, as in so many other cases.

13. One of the victims wrote to us in the following terms, which bears repeating in full:

> *"From our experience the UK Govt has been evasive, dishonest and cynical. The D of H has been hostile in it's responses to campaigners and MPs who have debated in Parliament. They have refused to both fully accept responsibility and to offer realistic compensation. They have engaged in political trickery and treated victims with contempt. The D of H clearly has a lot to hide and has been aggressive in defence of it's own interests. The financial assistance given has been piecemeal and grudging.*
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> *The use of contaminated blood and its consequences is a scandal but the attitude of the D of H to victims is an even bigger scandal, provoking great anger, distress and suffering adding insult to injury."*

14. The bereaved partners who cared for the victims, often giving up their own careers to do so, had to rebuild their lives (often whilst caring for their children) and the tap was turned off on the trickle of financial support three years after the death. Thereafter they were left to fend

for themselves. We say this is unacceptable. One widow who we represent wrote to us in the following terms:

> *"All widows have been given a life sentence, some a double life sentence if infected as well, for a " crime " we did not commit and we suffer daily from something we did not do. We have been there when our husbands have discovered that they have become HIV positive and / or Hepatitis C positive We have watched our loved ones become ill. We have often given up our jobs and careers to nurse and care for them enduring hardships in consequence. We have had to endure the stigma of these illnesses with them. We have suffered harassment and prejudice and have often been too frightened to tell our families about the truth of loved ones , perhaps lying or keeping secrets. We have had to tell our children ,if we have been able to have them , that their father was ill and dying while others have been denied the chance of ever having children.*
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> *We have watched our loved ones slip away, hold their hands as they do and see them die horrific deaths, bury them and afterwards try to re-build our lives with the constant background of this travesty in our minds and with little support. Many have been unable to work again , been traumatised ,had breakdowns and been left to become single parents and bring up children who have been left without fathers A few widows have become homeless or have committed suicide."*

15. Sir, a recurring theme is the great difficulty people have faced in obtaining their medical records and that when the records have been obtained, they have crucial periods missing from them or reveal that the medical practitioners knew of the infection long before they informed the victim.

16. One striking example of this involves a teenager, a haemophiliac, who went to Australia for a year with a supply of Factor VIII given to him by his treating consultant in Cardiff. Whilst in Australia he suffered a bleed in his kidney and used his Factor VIII to treat it. Subsequently, his mother, whilst speaking on the telephone to his consultant in Cardiff, was told that he had HIV. She was told not to tell her son until the consultant had spoken with him. Thereafter, she discovered that her son was told by the consultant that he had HIV but that he should not tell anyone and keep it "*strictly confidential for his own good*". Years later as a result of a civil claim, his mother had disclosed to her a letter written by the consultant at Cardiff to the doctor in Australia which said that it was known in 1983 that the young man had received Factor VIII from a batch used for a patient in 1980 who had subsequently developed AIDS. The letter went on to ask the Australian doctor to keep "*a gentle eye on him without letting him know the reason why. I do not anticipate any trouble but I think it would be remiss of me not to follow things up*". He was not told until the end of 1985 that he had HIV - over 18 months after this letter. This and other important material only became apparent following careful analysis of his medical records.

17. Clearly, one of the most important functions of this Inquiry is to facilitate every person who wants to give their account of what happened to give their evidence and to listen to them. It goes without saying that that evidence should be as accurate as possible.

18. We know that the Inquiry appreciates this and is in the process of ensuring that between now and the end of January 2019 everyone who wants to, can give a witness statement.

19. As part of the process of making a witness statement, it is vital that witnesses are able to refer to the contemporaneous medical records. It would be wholly unacceptable for people who may be vulnerable

and/or traumatised to be left to make their witness statement from recollection of events, which may have taken place over 4 decades ago, without the assistance of contemporaneous records. This should not become a memory game. Moreover, individuals cannot recollect what they were not told.

20. The very important point is this, in order to enable the victims to truly give the evidence of what happened to them, their medical records must be reviewed prior to their witness statements being prepared. Surely this is uncontroversial.

21. Yet, it has been suggested by the Inquiry team that our clients should obtain their medical records by themselves, if they wish to review them. This is an unsatisfactory state of affairs. Sir, you will know only too well how difficult it can be to obtain all relevant medical notes and then to decipher them. It is often the experience of those representing injured persons that their medical notes can be found in many locations, sometimes where they might not be expected to be found. To put it shortly, they need to be traced. We call on the Inquiry to promise the victims that they will be assisted, by their legal representatives if they so wish, in obtaining their medical records and understanding them.

22. One of the trustees of Haemophilia Wales explained to us last week the difficulty he had in obtaining his own medical notes. When he initially requested them, he was supplied only with a disc containing his haemophilia centre notes from 1983 onwards. His insistence that this could not be the sum total of his notes in existence led him to a meeting with a legal team at Cardiff & Vale University Health Board two weeks ago Thereafter, an investigation was carried out and four files of his notes were found in archives, together with the notes of many others. This is a good example of the difficulties involved and why the victims

are entitled to representation to ensure that they obtain their notes in full, in so far as they still exist.

23. A further complicating factor is the short time-scale for the production of witness statements once a witness cost award has been made; just 21 days. This makes it impossible to obtain and review medical records before the production of a witness statement. We invite the Inquiry to extend that time period so as to allow that process properly to happen.

24. If this is not done, then the Inquiry will fail in this singularly most important function and the victims will not be able to tell the Inquiry their story as in a large number of cases they will either of forgotten various events or dates or they won't know all of the detail – because it has been hidden from them by those they trusted most.

25. More generally, patters of behaviour and misconduct disclosed in the medical records will only be identified if each and every set of medical records is reviewed.

26. It is already overwhelmingly apparent to us that the medical records have a story to tell. This Inquiry must allow that story to be told.

27. Finally on this matter, it is important that the victims are able to give their evidence in their own words. If this includes strong, frank language, then so be it. This also includes their ability to give evidence in their mother tongue. We know of at least one core participant who wishes to give evidence in Welsh.

The Truth

28. Moving on, what else do the victims want? They want the truth. When do they want it? 30 years ago. The victims are angry that the

Government has not faced up to what happened before now and accepted responsibility During those years, they have fought tooth and nail for everything, including treatment and financial support. Not only that, but because of the stigma attached to Hep C and HIV many of the victims kept their ill-health secret so that consequently, they did not know the extent of the disaster and thought they were the only ones.

29. Many of the victims have campaigned for 30 years for a public Inquiry and **this Inquiry** is the first and the last opportunity for the victims to know the truth about why, for what reasons and in what circumstances they were exposed to contaminated blood products. It is of the utmost importance, and they know that it is your intention, to get to the truth of what happened.

30. What do they want the truth about? In one sense, the answer to the question is quite simple and straight forward – they want to know the truth about everything concerning the desperate position in which they have been placed by the actions of others. They appreciate, however, that you seek something a little more specific today and so in essence they seek the truth about the following matters:

   a. American drug companies;
      i. They want to know why the ADCs chose to buy blood from prisoners, drug addicts on those on the edge of society when they knew that there was a substantially increased risk that the blood would be contaminated with Hep C and then eventually HIV;
      ii. They want to know when and in what circumstances the DCs came by this knowledge;

    iii. They want to know what information regarding this risk the DCs gave to the purchasers of this blood, in particular the UK Government and health services;
    iv. If they did give information or warnings to the UK Government or health services about the increased risk of contamination of blood products then what did they tell them and when, to whom and in what form was that information transmitted;
    v. They want to know what measures if any were taken to avoid or materially reduce the risk of the blood products being so contaminated. In particular, what measures were taken to test individual donors to discover whether their blood was contaminated with Hep C or HIV;
    vi. They want to know if the DCs adopted a different policy regarding warnings of the increased risk and measures to avoid or reduce that risk in regards to their dealings with the American Government and health services. In other words, they want to know the extent to which the ADCs discriminated against non-Americans;
    vii. They want to know about the methods of production of blood products adopted by these companies in regard to the blood harvested;

b. Self-sufficiency;
    i. They want to know why it is that by the early 1970s the UK was not self-sufficient in the production of **safe** blood products;
    ii. They want to know why it is that when the UK Government and health services started to become aware that the BPs they were buying from the ADCs might be contaminated with Hep C / HIV, measures were not immediately put in place to enable the UK to be wholly self-sufficient in the production of safe BPs;

    iii. They want to know what information was provided to Lord Owen, Dr David Owen, Minister for Health (as he then was), in 1974 that made him so concerned regarding the contamination of BPs purchased from America that he directed that measures should be put in place to become self-sufficient within 5 years; they want to know why it took more than 13 years to reach self-sufficiency in England & Wales. By way of comparison we see that Ireland, who also set a period of 5 years to achieve self-sufficiency, achieved it in that timescale;
    iv. They want to know how Scotland became self-sufficient in the production of BPs at an earlier date than the rest of the UK;
    v. They want to know why, despite the fact that Scotland had available surplus capacity to produce BPs, the UK Government or the health services failed to make use of it;
    vi. They want to know what happened to the money that Lord Owen set aside to achieve self-sufficiency in 5 years;
c. Role of UK Government:
    i. They want to know what enquiries or investigations were carried out by the UK Government regarding any potential risks posed by the purchase of BPs from ADCs;
    ii. They want to know if any enquiries or investigations were carried out, what prompted them;
    iii. They want to know what information was obtained and was it acted upon;
    iv. They want to know what enquiries or investigations should have been made by the UK Government to ensure that any BPs purchased from America were safe;

v. They want to know when, by whom and in what circumstances the UKG first became aware that the use of BPs from ADCs posed a risk to UK citizens;

vi. They want to know to what extent there was co-operation between various departments of Government and in particular, why was contradictory advice given by various departments;

vii. They want to know what actions if any were taken by UKG when they became aware of the risks posed by BPs purchased from ADCs;

viii. They want to know what guidance if any was given to the health services regarding the potential risks posed by BPs purchased from ADCs;

ix. If none was given, why not;

x. They want to know why did the Government not impose an immediate prohibition on the purchase of BPs from ADCs when the risks became known;

xi. They want to know why wasn't there a uniform system of procurement, either by the establishment of a central agency or by the issuance of guidance;

xii. They want to know to what extent was the purchase of BPs from ADCs influenced by conflicts of interest / commercial interests held by the ADCs and/or UK Government which resulted in known risks being disregarded or minimised;

xiii. They want to know what investigations and measures if any were taken to ensure that BPs produced in the UK were safe;

xiv. They want to know why is it that so many relevant documents, for example those put before Lord Owen, have been destroyed or lost;

        xv. They want to know why did the Government not permit a public Inquiry before now;
        xvi. They want to know why did the Government fail to provide witnesses to the non-statutory Archer Inquiry;
        xvii. They want to know to what extent has there been a conspiracy of silence on the part of Government;
        xviii. They want to know why has the Government failed to put in place a comprehensive, UK wide system of compensation for the victims;
        xix. They want to know why is there such variation in the systems set up for the administration of financial assistance;
        xx. They want to know why are there different categories of victims that receive different levels of financial assistance, in particular why has there been rank discrimination against widows;
        xxi. They want to know what role if any did the drug licensing authorities play in authorising or permitting the supply of potentially contaminated BPs;

d. Devolved Government;
    i. As the majority of our clients have a particular interest in Wales and Northern Ireland, it is necessary to consider whether the differences in the form of government will lead to different considerations which will require careful examination; in particular, the chain of responsibility for decisions and/or actions and what were the practical differences in outcome;
    ii. Looking at NI;
        1. From 1970 to 1972 it had its own parliament at Stormont with full responsibility for health;

    2. From 1972 to 1999 there was a period of direct rule when it appears that the Secretary of State for NI had some responsibility for health;
    3. From 1999 to 2002 there was a devolved assembly which had responsibility for health;
    4. That was followed by a period of direct rule when some responsibility for health appears to have reverted back to the SSNI;
    5. From 2007 responsibility returned to the Assembly;
    6. More recently, the constitutional position is unclear, as the Assembly is suspended, and so it is unclear what role the Secretary of State for NI is carrying out;

iii. The Northern Ireland victims want to know the extent to which the different structure of government and the different decision making processes that existed may have led to an enhanced risk of contracting Hep C / HIV and further, the impact this may have had on the provision of care and treatment in that country;

iv. In respect of Wales:

    1. From 1970 to 1999 the Secretary of State for Wales had some responsibility, the extent of which is unclear, for the health service. The letter from the Chief Executive of the Cardiff and Vale University Local Health Board, dated the 12th of September 2018, makes it clear that until 1988 regional blood transfusion centres were managed by regional health authorities, with the Welsh Office managing the Cardiff transfusion centre. Further, the Haemophilia Centre based at the University Hospital of Wales acted autonomously when it

        came to the selection of blood products. It would seem that it may have have managed by the SSW;
    2. From 1999 onwards, as a result of devolution, it is the WAG that has undertaken responsibility for health and the provision of health services;
  - v. The Welsh victims have similar concerns to those in NI regarding the extent to which there were differences in the form of government and the decision making process which may have exposed them to an enhanced risk of harm and resulted in different provision of health care;
  - vi. It may well be that the Inquiry will benefit from expert evidence on the respective constitutional arrangements, formal and informal, in Wales and Northern Ireland;
  - vii. We invite the Inquiry to consider whether the various offices of the Secretaries of States or devolved governments possess or have access to copies of documents that have been lost or destroyed by central Government;
- e. Health Services;
  - i. They want to know what responsibility did individual health authorities (a term used in a general sense), including but not limited to hospitals and haemophilia centres, have for the selection and purchase of BPs;
  - ii. They want to know to what extent did those bodies have or should have had a uniform policy for the purchase of BPs;
  - iii. They want to know what measures if any were taken by those bodies to collaborate with each other in the safe provision of BPs;
  - iv. They want to know what measures if any were put in place by those bodies to ensure that only safe BPs were obtained;

v. They want to know what measures if any were put in place by those bodies to ensure that BPs produced in the UK were safe;

vi. They want to know why they failed to ensure that users or potential users of BPs were given appropriate warnings or advice regarding the potential risks they faced regarding the use of contaminated BPs;

vii. They want to know why they failed to establish a system and/or policy for advising haemophiliacs of alternative methods of treatment that could have avoided or materially reduced the risk of infection from BPs – why was it left to individual medical practitioners to decide what advice to give;

viii. They want to know why they failed to establish a system for informing victims that they had contracted Hep C / HIV;

ix. They want to know why they failed to establish a system for the provision of counselling and other support services to victims after they were diagnosed with a Hep C or HIV infection;

x. They want to know why they failed to establish a system for the provision of information regarding the risk of contamination of their partners or other members of their family and how those risks could be minimised or otherwise managed;

xi. They want to know why has there been a wide disparity in the type and quality of treatment and support services offered to those who have suffered injury as a result of treatment with contaminated BPs;

xii. They want to know to what extent was the purchase of BPs from ADCs influenced by conflicts of interest / commercial interests held by the ADCs and/or health services which resulted in known risks being disregarded or minimised;

xiii. They want to know what actions if any were taken by these health authorities in response to the developing knowledge of the risks associated with BPs purchased from ADCs and those produced in the UK;

xiv. They want to know why they failed to ensure that informed consent was obtained for treatment with BPs in respect of which there was a risk of contamination;

xv. They want to know why they failed to ensure that informed consent was obtained for carrying out tests on victims blood or tissues;

xvi. They want to know to what extent were the victims used as Guinea pigs in regard to the treatment they received or did not receive;

xvii. They want to know why they have failed to attempt to trace those individuals who were at risk of being exposed to contaminated BPs especially those who may have received blood transfusions;

xviii. They want to know why some patients' records been wrongfully interfered with including the removal of those parts of the records dealing with the likely date and circumstances of contamination; the subsequent testing of the patients blood to confirm contamination; and the period between when the medical practitioners knew of infection and when the victims were informed;

xix. They want to know why so many death certificates contain inaccurate or wholly misleading causes of death when the true reason, death caused by Hep C or HIV, would have be clear and obvious from the known history of the deceased;

xx. They want to know to what extent has there been a conspiracy of silence on the part of the health authorities;

f. Medical Professionals;
    i. They want to know has there, since the 1970s, been a conspiracy of silence amongst medical professionals regarding (i) what was known about the supply of contaminated blood; (ii) the fact that patients had developed Hep C and/or HIV; (iii) the testing of patients' blood without their consent; and (iv) the failure to obtain informed consent for treatment, in particular for treatment which was avoidable;
    ii. They want to know why were victims consistently not told that they had contracted Hep C and HIV notwithstanding it was recorded in their notes;
    iii. They want to know why doctors failed to inform patients (in particular mild haemophiliacs) of the alternatives to treatment with blood products potentially contaminated with Hep C and HIV;
    iv. They want to know why they failed to inform victims of the risk of infecting their partners or other members of their family;
    v. They want to know to what extent were the treating consultants, in particular those in charge of haemophilia centres, autonomous in the choice of BPs;
    vi. They want to know if they were autonomous, what was the basis upon which decisions were made regarding the purchase of BPs;
    vii. They want to know why doctors failed to warn patients of the known risks of exposure to contaminated BPs.

31. Sir, when considering the issues we just raised, we invite the Inquiry to consider the victims' view that the suffering caused by the initial industrial-scale infection was exacerbated by Government's and health services' inertia. Why did they signally fail to treat those who were injured by the NHS and blood transfusion services with dignity? It is little wonder that they grew resentful and bitter towards Government and the health services and assumed it was because the they both had something to hide (an inevitable reaction to the revelation that Lord Owen's ministerial papers had been destroyed without justification).

Justice

32. Thousands of people have died, thousands of people still suffer from very severe ill health and, tragically it is likely that in the future thousands more will discover that they have been infected with Hep C / HIV. The victims regard this inquiry as a search for justice. There is a general view amongst the victims that for over 40 years people in the know have kept their mouths shut, their files closed and their shredders busy. All they've received was a belated apology from Prime Minister Cameron in 2015. Where is the justice in that?

33. For the victims we represent, the following represent the absolute minimum requirements of justice.

Identify those responsible

34. They appreciate that the Inquiry can not determine questions of criminal or civil liability but nonetheless, they want you to name the names, they want to know the parties responsible for causing the devastating harm they have suffered; they want to know the parties responsible for causing them or their loved ones to be infected with Hep C or HIV; they want to know the parties responsible for causing

the deaths of their loved ones. The identification of those responsible is likely to include individuals and more likely to include institutions or their constituent parts. Decisions don't make themselves. Actions don't action themselves. Some body makes the decisions or omits to make a decision; some body acts or fails to act. It is only by identifying those parties responsible for what has been described as the greatest untold injustice in the history of the NHS that the victims will find some closure.

Provision of health services

35. As we have already noted and as we apprehend the evidence will reveal the provision of health services, using that term in the broadest sense, is a history of failure to meet the real needs of the victims. The picture that will emerge is a hodgepodge of ill-thought out initiatives where health authorities are left to their own devices and allowed to their own sweet way. In some areas more effective treatment is provided than in other areas. It is an affront to human dignity that the standard of treatment received or to be received will depend upon where in the UK an individual happens to live. By way of example we believe that the most effective drug for treatment of Hep C is universally available in Wales and NI, yet it is rationed in England.

36. The public is likely to be astonished at the variations in health services provided to victims in the UK. It brings this country into disrepute. The victims hope that this Inquiry will make firm recommendations as to how on a nationwide basis (and centrally funded) the highest quality of health services can be provided to the victims. As you will no doubt bear in mind, many of these victims already suffer from the highly debilitating and sometimes fatal condition of haemophilia – contraction of Hep C / HIV has gravely compounded their existing condition. More generally, these viruses have given rise to victims

developing severe medical conditions including cirrhosis and cancer of the liver. These various medical conditions frequently result in death. All of the victims require, and they would say are entitled to receive, comprehensive healthcare and support services of the highest standard.

37. Consideration should be given to the scheme established in Ireland after the Lindsay Inquiry where the victims are given a health card which enables medical practitioners to identify the victims as sufferers of the contaminated blood scandal so that no unnecessary discussion need to be had about the matter. A particularly important feature is that it also entitles them to priority treatment.

38. In addition, the health services should be required to trace and properly identify those individuals who may have been exposed to treatment by contaminated blood products. These people, going about their every day lives blissfully unaware that they may have developed Hep C or HIV, should be traced and when found, be offered blood testing and provided with such counselling, treatment and support as may be necessary - as was recommended in the Penrose Inquiry. Although we are aware that there have been some isolated attempts to trace such people, there is no nationwide procedure.

39. These services should not be handed down from on high but rather as the result of proper consultation with the victims of this medical disaster as to what treatment, care and support is to be provided and how it is provided. They want a voice in what happens to them and how they are treated. For over 4 decades up until the present time they have had to take what was handed out to them. Now they want to take ownership so far as possible of their treatment, care and support, permitting them to make informed choices in relation to their

treatment. What is sought is a recommendation that going ahead there's a partnership between health services, doctors and victims.

Compensation

40. In the past, the Government has set up and funded arms-length charitable organisations to distribute some financial support to some victims. More recently, there have been changes to the way in which these funds are administered, but any suggestion that this represents proper compensation for the hurt they have, they are and will continue to suffer, is met with anger and indignation. The system which has developed presents a patchwork of ill-thought out, badly funded, and discriminatory support. A recurrent complaint is that victims feel they have to go cap in hand like beggars to seek the bear minimum of support. It is discriminatory, derisory and demeaning. The byzantine complexity of the various schemes results in clear categories of victims, such as widows, receiving the absolute minimum of support. In some cases, entitlement to financial support depends on whether or not claims were registered by certain dates. That is arbitrary and capricious.

41. One doesn't have to look far for more generous and humane systems of support. In Ireland in 2002 the government, following a public inquiry and whilst denying liability, accepted responsibility and set up a far more sensible and generous scheme for the support of their victims of the contaminated blood scandal. One can imagine the distress felt by victims in the UK, a far larger and wealthier country, having to make do with the crumbs that fall off the table.

42. They look to this Inquiry to make recommendations for a comprehensive system for the payment of proper compensation, as might be understood by a personal injury lawyer, to the victims

without discrimination. A system where there will be no need to go cap in hand when an unexpected bill arrives on the door mat but rather compensation as of right. Compensation for those who have suffered, who continue to suffer and those who will suffer in the future so as to allow them to regain independence and some control over their lives. The first duty of a government must be to protect its citizens, where there has been a lamentable failure to do so, resulting in so many people, through no fault of their own, suffering such loss, the least that can be expected is a proper system of compensation.

Legacy

43. In order to ensure this Inquiry leaves a meaningful legacy, the victims believe that the issues we have raised on their behalf must be effectively addressed.

THEY MUST HAVE THEIR STORIES HEARD
THEY MUST LEARN THE TRUTH
THEY MUST RECEIVE JUSTICE